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Understanding environmental health disparities of Roma populations in Romania

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UNDERSTANDING ENVIRONMENTAL HEALTH DISPARITIES
OF ROMA POPULATIONS IN ROMANIA

A Dissertation
Submitted
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

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May, 2010

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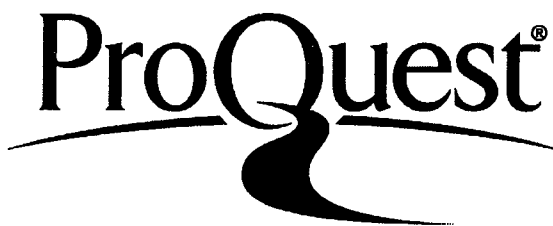
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DEDICATION

This research study is dedicated to my beloved father whose life was cut short from the toxic chemical of Agent Orange. I dedicate this dissertation in his memory, particularly the contribution it makes towards a deeper understanding of the effects that toxic chemicals have on health and human life.

ACKNOWLEDGMENTS

First and foremost, I would like to express my heartfelt gratitude to Dr. Catherine Zeman, my advisor and committee chair, for her assistance, support, and guidance in this research project. I am especially indebted to the experiences that Dr. Zeman and the UNI Recycling Reuse Technology Transfer Center afforded me in gathering information in Romania for the past three years. In addition, I am grateful for the extra time and resources that Dr. Deborah Gallagher provided me in putting together my qualitative methodology.

I would also like to sincerely thank Pastor Rufus Whynot and all the staff and volunteers from Yielded Vessels Ministries / Family Aid Foundation that made this research possible. Because of their time, support, flexibility, translation, access to “Pata Rat,” and connections to the Roma people, I was able to gain an in-depth understanding of the Roma’s environmental health situation in a positive working environment.

Finally, I would like to thank all the Roma people of Dallas who participated in the research activities and trusted me to share their everyday lived experiences. I am grateful for their hospitality and their invitations into their community, homes, and ultimately their lives. They inspired and encouraged me with their smiles and desire for a happy, healthy, and quality life.

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Approved:

Dr. Catherine Zeman, Committee Chair

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May, 2010

ABSTRACT

The Roma are the largest and most marginalized minority group of Central and Eastern Europe (CEE) with the highest number residing in Romania. Their problems and struggles are multi-faceted and deeply rooted in a long history of discrimination and stigmatization. Over the years, many strategies have been developed and implemented across CEE, yet very few studies have addressed their environmental and occupational health issues. Moreover, because the vast majority of these studies have employed quantitative methodology, they have had the unfortunate effect of dehumanizing and devaluing the Roma people through scientific reductionism.

The purpose of this study was to gain a deeper, more complex, and nuanced understanding about the Roma people, one that accounts for the historical, political, social, cultural, and environmental contexts that shape their everyday lived experiences. Using an arts-informed qualitative research methodology, the aim was to achieve an in-depth understanding of how the Roma make sense of and cope with the conditions under which they have been forced to live and work.

A variety of qualitative methods, including ethnographic observation, participatory community mapping, semi-structured interviews, photovoice and photography were used to engage with the Roma of Dallas, a community that lives and works off the municipal landfill outside Cluj-Napoca, Romania. Through this methodological approach I sought to counter the devaluation of these people and provide knowledge that will not only better inform future studies and potential solutions but will also directly address the stigma that is apparent in their present condition.

A number of environmental and occupational health concerns were revealed through the course of the study including water, air, and soil contamination; lead and chemical exposures; poor hygiene and sanitation; and a disproportionate level of disease and illnesses. Results are communicated through the use of maps, images, and narrative in Chapter Four. Conclusions address basic human and community rights concerns and discuss both social and environmental justice issues. Recommendations are made in the areas of environmental and occupational health for improving the lives of Roma and scavenging communities in CEE and around the globe.

CHAPTER 1

INTRODUCTION

No one's immune, invulnerable. So it's important to get exposed to local stories that bring us into worlds of experience that are unknown to us, show us the concrete daily details of people whose lives have been underrepresented or not represented at all, help us reduce their marginalization, show us how partial and situated our understanding of the world is. (Ellis & Bochner, 2000, p. 748)

The Roma are the largest and by far the most marginalized minority group of Central and Eastern Europe (CEE) with the largest population residing in Romania. Their problems and struggles are multi-faceted, numerous, and deeply rooted in a long history of discrimination and stigmatization. Over the years, many strategies have been developed and implemented across CEE, yet very few studies or programs have addressed Roma environmental and epidemiological health issues (Zeman, Depken, & Senchina, 2003). Moreover, because the vast majority of these studies employ quantitative/positivist methodology, they have had the unintentional and unfortunate effect of dehumanizing and devaluing the Roma people through scientific reductionism. In other words, the demands of scientific inquiry and writing have not allowed for Roma voices to come forward. Consequently, their lives, and therefore the people themselves, have been reduced to observable and quantifiable variables. In turn, one can trace, at least in part, the inadequate implementation of “solutions” to address their dire circumstances to the decontextualizing effect of this research approach. Thus, their marginalization has sometimes been compounded rather than alleviated.

The purpose of this study is to gain a deeper, more complex, and nuanced understanding of the Roma's environmental health conditions, one that accounts for the

historical, social, political, and cultural contexts that shape their everyday lived experiences. Using a variety of qualitative research methodologies with participatory methods, the aim was to achieve an in-depth understanding of how the Roma of Dallas, a community that lives and works off a municipal landfill outside Cluj-Napoca, Romania, make sense of and copes with the environmental conditions under which they live. An added dimension of this approach was its potential for privileging the voices of a people whose voices have all too often, and all too effectively, whether intentionally or unintentionally, been silenced.

The Roma people face a disproportionate amount of environmental health disparities due to poverty and marginalization. Some Roma communities in Europe even live on toxic lands among extremely hazardous environmental conditions (ERRC, 2006). Many are either located in highly polluted areas which lead to serious and irremediable effects on their immune system (Cace, Constatin, Dediu, Macioi, & Stefan, 2006), or areas where access to water and sewage treatment is absent or limited (Steger & Filcak, 2008, p 50). The Roma community of Dallas and communities of “Pata Rat” are among the Roma communities across CEE living in hazardous environmental health conditions. These communities mirror the Roma situation all over Romania and countries in Central and Eastern Europe (CEE).

Hundreds of thousands of Roma, particularly in Slovakia, Romania, Bulgaria and in parts of the former Yugoslavia, live in settlements with limited access to clean water, sanitation or basic medical care. Many of these settlements, like the one at Pata Rat on the outskirts of the city of Cluj-Napoca, in Romania pose additional health threats for the Gypsies that are living there. (Pogany, 2004, p. 1)

The Roma communities of “Pata Rat” are located approximately five kilometers outside Cluj-Napoca in Transylvania, Romania, in an industrial area near the city’s municipal landfill. Pata Rat is the name of the public road leading to the municipal landfill, which spreads 8.96 hectares (22.14 acres) and 10-15 meters (32-49 feet) high. It has also widely been associated with the Roma that reside on and around the landfill and has further deepened the stigma that they are dirty and from the dump. There are actually three communities living within a mile of the landfill and all have been referred to as “Pata Rat.” They are Rampa Degunoi, Dallas, and Cantonului (M. Lakatos, personal communication, May 19, 2008). The Family Aid Foundation and locals also identify “Pata Rat” differently too. Some combine Rampa Degunoi and Dallas as “Pata Rat” because Pata Rat Road runs alongside both communities. Cantonului or Canton is referred separate of “Pata Rat” because it is located on Cantonului Road (C. Aschilean, personal communication, March 2009).

Rampa Degunoi is located in the landfill area. It was once comprised of approximately 100 Roma until the morning of July 16, 2008, when representatives from police, city hall, the Prefect Board, 35 peace officers, and three dogs raided the community. Dozens were forced to evacuate. If they had legal documents from other counties they were told to return to that county, and, if not, they were forced to evacuate, and were not provided assistance in what to do next. It was reported that the Roma set fire to their homes in protest (Costin, 2008). This is not the first time such forced evacuation and acts of violence have taken place in “Pata Rat.” In November 2005, over 80 policemen with special intervention forces raided the community twice and resulted in

at least five Roma injured and the burning of 15 Roma homes (Centre on Housing Rights and Evictions [COHRE], 2008). Roma men and women were reportedly abused, suffered various degrees of violence, and lost their homes. They claimed that police left them, even small children, “under the open sky, in cold conditions” (Office for Democratic Institutions and Human Rights [ODIHR], 2007). Then again on August 2, 2006, community police and representatives from Cluj-Napoca City Hall burned 10 Roma homes and reportedly abused three Romani women (COHRE, 2008). The forced evacuations are expected to continue until all Roma of “Pata Rat” without legal forms are evacuated (Costin, 2008). It is unclear which of the three communities of “Pata Rat” were affected during these raids, but it is believed to be both Rampa Degunoi and Dallas. Raids like these have been going on throughout Romania since the early 1990s in which homes in over 30 Roma settlements have been set fire. The community of Dallas is located approximately 1-2 km down the road from the landfill and is home to between 550-600 Roma. The community of Cantonului, located the farthest away from the landfill, is home to approximately 350 Roma (M. Lakatos, personal communication, May 19, 2008). Together there are approximately 1,000 Roma living in “Pata Rat.”

For the present study, the Roma community of Dallas will be explored and will be referred to as Dallas throughout the study. This reference is made intentionally to help bring forth their identity separate of the landfill and also separate from the other communities also known as “Pata Rat” both of which have long marked their identity. When “Pata Rat” is referenced however, it is because through others’ research there were times when I was unable to differentiate which community the researcher was talking

about and/or I am making a recommendation for all three communities, including Dallas.

Figure 1 illustrates the layout of the “Pata Rat” area. The line connecting the communities is Pata Rat Road and serves as the main route the Roma travel to and from the landfill with their horse-drawn wagons or by foot. The road is also how the garbage trucks and other transit go to and from Rampa.

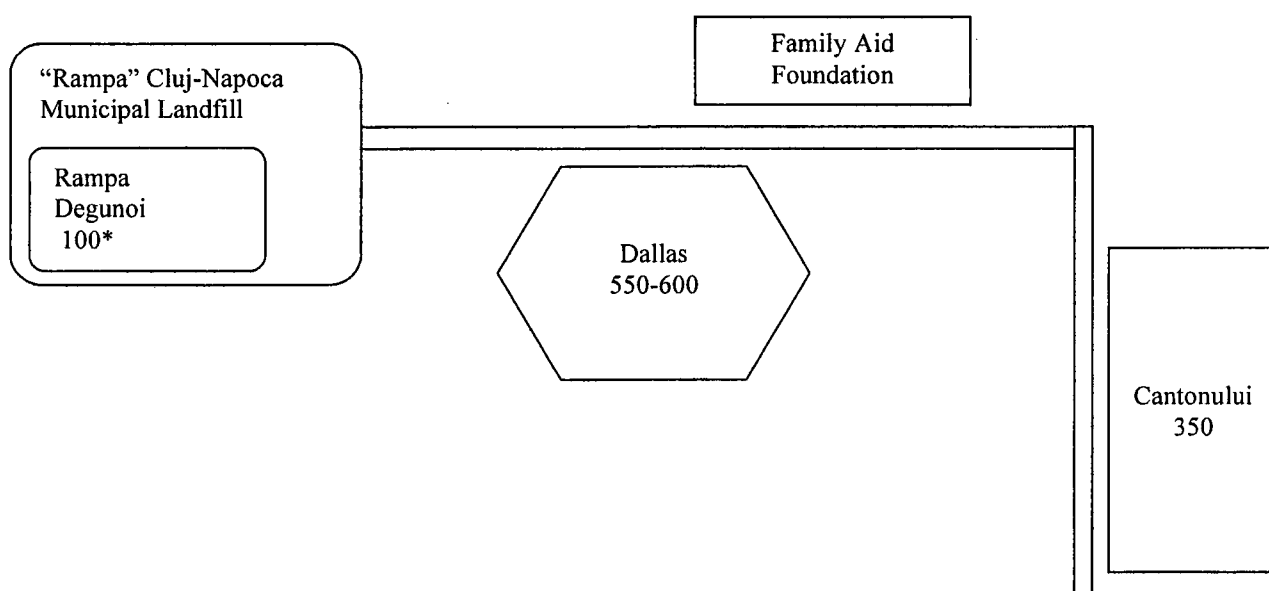


Figure 1. Layout of “Pata Rat” area

Many community members in Dallas arrived in 1989 after the fall of Communism. The transition to a market economy caused the closing of agricultural farms and state owned enterprises where many of the Roma held jobs. They were the first to lose their jobs, were unable to find alternative work and therefore unable to pay rent and “survive.” This led many Roma to “Pata Rat” where they found ‘work’ in scavenging the local waste platform. This has since strongly marked their identity and

reinforced the stigma of being “dirty and smelly” and a “health hazard.” Unfortunately this process destroyed much of their trust, the little they had, in non-Roma people and institutions (Stanev, Veraart, & Popovici, 2005).

The majority of community members from Dallas, including women and children, make their sustenance by scavenging Rampa. Communities involved in scavenging are considered to have two characteristic aspects: education is not considered to be of high importance and children are expected to take part in the work (Stanev et al., 2005). This is consistent with many of the children of “Pata Rat” who work in the landfill. During a visit made by Green Partners in 2004, children told them,

During summertime when they are not going to school, they spend most of their days on the landfill. Some even improvise provisional huts for the summer, so they can spend the night on the site and be bale [*sic*] to be the first ones to collect when the trucks that dispose of waste arrive. (Stanev et al., 2005, p. 15)

The children live in a closed, socially marginalized community, where they eat, sleep, play, spend time with their parents, and ultimately work to help their parents. Besides possibly school, this is the only community they are familiar with. Even if their parents have known a different environment, many of the children in Dallas have not. They were born in the vicinity and have rarely, sometimes never, experienced another environment. Thus, many of them cannot imagine a different way or course of life besides the one that they have grown up in (Stanev et al., 2005). For the children who are lucky enough to go to school, they still face a number of obstacles and discrimination that further marginalize them.

Dallas is located on private property and is not part of the Cluj-Napoca municipality; therefore the Roma do not officially have legal status to be there. Without

legal status, they are unable to get identity cards and thus access to social services. Those that hold identity cards are often from different counties so they too are unable to get access to the health and social services they need (Stanev et al., 2005). The process of obtaining the appropriate documents is long, costly, and difficult. Roma Health Mediators (RHM) are available to assist Roma communities; however, “Pata Rat” has only had one health worker who was employed for about six months during a pilot program in 2006 (RCRC, 2006). Fortunately, emergency ambulance services are available (CEDIME-SE, 2001), and more recently starting in Spring of 2009, weekly 3-hour visits from a local physician and nurse are being provided at the local health clinic (R. Whynot, personal communication, May 2009). This weekly service is important and valued by the people of “Pata Rat” where digestive, lung, and circulatory system diseases are frequently encountered. They also suffer from malnutrition and vitamin deficiency disorders such as anemia and rickets (Arpinte et al., 2002).

In addition to their lack of health and social services, the health status of the Roma of “Pata Rat” is greatly affected by their physical and built environments. The build up of solid waste in the community results in toxic chemical exposures through air, soil, and water contamination. This means the Roma are in constant contact with numerous toxicants that are likely to have serious and irremediable effects (Cace et al., 2006). What is more frightening and unacceptable are the combinations of chemicals they are exposed too. Very little is known about the possible effects from potential interactions of the multiple chemicals with which they come in contact (Kerns, 2001). Poor hygiene and sanitation also contribute to higher doses of exposure.

Water sources are improperly managed or broken and there are visual signs of contamination including solid waste and feces, both human and animal. “During the year 2000, three children died and several adults were hospitalized due to the problems related to bad quality of water” (Arpinte et al., 2002, p. 16). The water sources that are connected to the city pipe system are inadequate as the water pressure can often be insufficient, forcing Roma to use alternative water sources at the risk of catching disease. Moreover, the wells that are available to the community were not dug deep enough, so they sometimes freeze during the winter months (F. Moisa, personal communication, May 18, 2008). Latrines, many of which are not managed properly, are scattered throughout the community and several are in close proximity to water sources. Families, who do not have a latrine, urinate and defecate outside their home (Dallas community members, personal communication, May 2008).

A major reason for the Roma of Dallas’ lack of progress is that the local government and some nonprofit organizations view “Pata Rat” as a temporary problem, one that is going to go away (F. Moisa, personal communication, May 18, 2008). The Cluj-Napoca City Council has actually stated this openly since 1996 with annual threats to close down the municipal landfill, which happens to be the only source of income for the majority of the “Pata Rat” people (R. Whynot, personal communication, May 2008; Stevenson, 2007). This would mean that most of the Roma residing there would lose their ‘jobs’ and be forced to migrate. This lack of both job and land security leads to a lack of development in Dallas and contributes to poor housing and poor environmental health.

Over the years, organizations have implemented development programs and activities to improve the situation of the Roma in “Pata Rat.” Unfortunately, despite these efforts, the community is still in serious need of attention and change, more specifically in regard to their environmental health conditions. The need for children to stay home and scavenge, the cultural and personal distrust of the Roma towards Gadge or non-Roma, and the lack of funding to provide needed programs, among other factors, create constant barriers to immediate change. Nonetheless, programs and organizations have worked hard and continue to work hard to make positive changes in “Pata Rat” and for the people who live there.

For example, an “I Want to be Healthy” project was initiated as part of a national effort called the PHARE program “Support for the National Strategy for the improvement of the situation of the Roma.” Its implementation was made possible by a grant component from the Resource Center for Roma Communities. Activities of the project were implemented in “Pata Rat” and included a health promotion campaign where informational materials were distributed on family planning, the importance of signing-up with a family doctor, TB prevention, and other health education topics. A second activity of the program trained four health workers with one hired for the duration of 2006. Other important activities included the construction and launch of a health station and medical tests designed to identify numerous illnesses (Resource Center for Roma Communities [RCRC], 2006). Unfortunately, after visiting with both the Resource Center for Roma Communities and the Foundation for Helping Families, it was discovered there is no longer a health mediator working with the community and the health station is

under-utilized. This is in part from lack of funding, resources, and people willing and able to serve in “Pata Rat.”

Another program implemented for the children from “Pata Rat” was the preschool of Tara Minunilor or “Wonderland” that opened its doors to 14 Roma children, ages 3-6, on June 6, 2003. Instead of taking in the capacity of 30 children they kept the number at 14 with the goal that they could attend regular classes with a common curriculum in the fall of 2004. The program was part of the “Children First” PHARE-RO program and its objective was to assure educational integration of children reaching school age. The program functions from nine to five, includes breakfast, lunch, personal hygiene, and educational activities and is run by four educators, four specialized school psychologists, two social assistants, and two attendants (Stanev et al., 2005). The program was still available in 2007 and had informational signs on community message boards in both Dallas and Cantonului. A Dutch organization also currently provides early childhood education programs three mornings a week in Dallas for about 15 children in a building donated by YVM/FAF. The program started sometime between June 2008 and May 2009.

In 1996, Medecins sans Frontieres (MSF), a French NGO initiated and funded a program for Roma children from “Pata Rat” to attend special classes at Someseni Elementary School. Children, ages 9-15, began taking part in a support-school system with an adapted curriculum, similar to one used for children with learning disabilities. The workload is lighter. Basic reading, writing, and arithmetic are the major focus, and

there are personal hygiene classes and a weekly Roma language class. In addition, time is allotted for assistance in completing their homework (Stanev et al., 2005).

Although putting children in special education classes may be well intended, it many times ends up doing more harm than good because it further adds to the stigma (Blomgren, 1993) that children from Dallas experience. Through interviews with students who had grown up in special education classes in the U.S., Blomgren (1993) discovered some common consequences of being labeled and segregated in special education. Themes included the issues of exclusion and marginality as well as the struggle to be recognized as human. Labeled students tend to be viewed as a problem that slows down the general productivity of the classroom. Special education students are taught and learn a much lower level of curriculum with lower expectations, which puts them at a disadvantage in society. Feelings of being different, anxiety, self-doubt, feelings of inadequacy, alienation, and a lack of confidence are common among segregated students. These feelings greatly contribute to one's ability to access human, social, and cultural capital therefore perpetuating the vicious cycle of extreme poverty (Blomgren, 1993).

In some countries, as many as 90% of Roma do not complete primary school and of those children, between 50-85% attend schools intended for the mentally and physically disabled (Decade of Roma Inclusion, 2005). If not placed by the school system, many times Roma parents choose to place their children in "special schools" because of discrimination they experienced in the regular schools.

Roma parents sometimes feel they are protecting their children by sending them to special needs schools with other Roma children, but the education they receive there ill prepares them for life, again exacerbating the risks of poverty and exclusion over the long term. (Ringold, Orenstein, & Wilkens, 2003, p. 7)

Following research to determine whether the students from “Pata Rat” could be integrated in the public school, it was determined that most were not capable. The ones that proved to have the required achievement levels were at least two years older than the age of the children in their grade level. Data collected from the study showed that the majority of children dropped out of school after finishing only the 4th grade. The study was unable to determine if their incapacity was related to the environmental conditions of their community and the influence the landfill had on the health condition of mothers and infants (CEDIME-SE, 2001).

The major support system and catalyst for change for Dallas and the “Pata Rat” people is and has been the Family Aid Foundation (FAF), a community-based outreach program under their United States-based nonprofit Yielded Vessels Ministries (YVM). The faith-based nonprofit, founded and directed by Pastor Rufus Whynot, has worked hard to provide spiritual, housing, health, and education programs for the Roma of “Pata Rat” since 1997. They have helped improve the Roma’s living conditions and have built 23 homes for Roma families. With their support and long-term commitment to the “Pata Rat” people, organizations, and researchers have been able to implement programs. FAF has done this by providing access and support to “outside” organizations and researchers including the University of Northern Iowa Study Abroad Program and me for the last three years.

The Yielded Vessels Ministries/Family Aid Foundation (YVM/FAF) was the community organization involved in the academic-community relationship in which the University of Northern Iowa (UNI) and “Iuliu Hațieganu” University of Medicine and Pharmacy in Cluj-Napoca (UMF) played the academic role. Academic-community relationships play an important role and Brown (2003) points out that they can provide crucial information needed by funding agencies and encourage innovative relationships. Moreover, the relationship has provided benefits to the Roma people in the form of outreach and education, benefits to YVM/FAF in the form of donations and expansion of their programming, and benefits to the academic community in the form of research and cross-cultural educational opportunities for students. It was through this academic-community connection that I was able to build a relationship with YVM/FAF staff and volunteers and ultimately the Roma people of “Pata Rat.” These relationships were further influenced by both the manner in which I approached YVM/FAF, and the Roma people and the understandings and agreements that we all reached together (Eisner, 1998). A brief discussion of how these relationships were built and maintained over the course of this study is important for understanding the value of the academic-community connection. This is especially true for future organizations and researchers who plan to work with Roma and other marginalized communities.

I first traveled to “Pata Rat” in May 2007 when Dr. Catherine Zeman, Professor and Director of the UNI Recycling and Reuse Technology Transfer Center (RRTTC), provided me the opportunity to observe the UNI Study Abroad outreach program at the YVM/FAF’s “New Life Education Center.” The program was part of the annual course

on “Environmental Health Disparities and Justice” offered at the Institute of Public Health at the “Iuliu Hațieganu” University of Medicine and Pharmacy in Cluj-Napoca, Romania and taught by Dr. Zeman.

After observing the academic-community-based outreach program I was fortunate to take part in the YVM/FAF’s three-day spiritual campaign later that week. At that time, I had the opportunity to walk through the communities of both Dallas and Cantonulie on three consecutive days. Members of YVM/FAF dressed as clowns and we handed out invitations as we walked, talked, smiled, and recruited participants. Over the four total days in the field I took several hundred photos. For the most part, everyone was excited to get their picture taken, only a few preferred not to, which I respected. This negotiation of consent that took place prior to taking the pictures was important throughout the research process. It provided an opportunity and created a moment where mutual understanding could be achieved and trust could be built.

In both May 2008 and May 2009, I returned to Dallas. With my observations and pictures from the year before, I helped UNI students deliver a culturally competent environmental health program that would fit the Roma’s needs. In 2008, the activities were designed to educate the Roma people, particularly women and children, about healthy hygiene and sanitation practices. On the first day participants learned about healthy hygiene practices and received hygiene bags that included two washcloths, two bars of soap, a toothbrush, and toothpaste. In addition, the women learned how to make “tippy taps” and were able to take a few home with them. Tippy taps are made from recyclable plastic bottles and are a way to provide running water for washing hands. On

the second day, parents learned how to make the oral rehydration solution while children learned about keeping their water wells safe. In 2009, the program focused on solid waste management, vector-control, and the importance of protecting your feet in and around stagnant water and waste. Participants learned how to manage waste to keep rats and rodents away from their home. In addition, parents learned basic first-aid and how to make flytraps from recyclable plastic bottles.

This annual outreach program has been a successful method in gaining access into Dallas in addition to the local people's trust. Moreover, it was done through fun, interactive, and educational activities that aimed to improve the Roma's health and well-being. The outreach program has made further accomplishments that are essential in improving the Roma's environmental health conditions. The UNI Study Abroad program addresses what the European Roma Rights Centre (ERRC) identifies as the four overlapping dimensions of accessibility: anti-discrimination, physical accessibility, economic accessibility, and information accessibility (ERRC, 2006).

First, the programs are anti-discriminatory because they are open to all Roma in the "Pata Rat" communities. The day before the program and for up to an hour prior to the start of the program, recruiters walk through the community and invite everyone to participate. The program is also physically accessible because it takes place at the Yielded Vessels Ministries/Family Aid Foundation's New Life Education Center, which is conveniently located across from Dallas and reachable by all communities of "Pata Rat." Economically, it is free to participate and participants receive resources that will enable them to improve their health and environment. Finally, all participants receive

information for improving their health that has been carefully designed to fit their needs, cultural practices, and educational levels. These four dimensions of accessibility (ERRC, 2006) will be discussed at greater length in Chapter 2, more specifically in their application to health programs.

Although I was able to gain access to Dallas and the Roma people through outreach and the YVM/FAF, I still needed to build enough trust so they would want to participate in my research study and share their environmental health concerns with me.

Data about living conditions and health status of Roma is hard to find. Lack of trust and negative experiences with health systems keep Roma people from engaging with health professionals, which results in a lack of awareness by policymakers of the specific health needs of Roma communities. (Open Society Institute, 2009)

To gain their trust, it was imperative that I employ a community-based participatory research approach (CBPR). The National Institute of Environmental Health Sciences (NIEHS) recommended six guiding principles for CBPR, which I utilized throughout the research process. They were to:

- Promote active collaboration and participation at every stage of research
- Foster co-learning
- Ensure projects are community-driven
- Disseminate results in useful terms
- Ensure research and intervention strategies are culturally competent
- Define community as a unit of identity. (O’Fallon & Dearth, 2002, pp.155-157)

In addition to following NIEHS’s guiding principles on CBPR, I used Participatory Action Research (PAR) as an important mode to gain further access and trust. PAR is a

collaboration of research, education, and action oriented towards social change and it has recently seen a dramatic increase of significance in the social and environmental sciences (Kindon, Pain, & Kesby, 2007). This research approach has commonly been used in the developing world and involves action research where researchers, like me, work with, for, and by the participants rather than perform the research on them. “Its strength lies in its focus on generating solutions to practical problems and its ability to empower practitioners – getting them to engage with research and subsequent ‘development’ or implementation activities” (Pope & Mays, 2006, p. 121).

Conducting action research required a more holistic approach that encompassed relationships and interactions between the participants and myself. It offered solutions to research questions that came directly from the Roma people. I not only extracted information from them, but I also recognized and used their local knowledge. The following were some basic principles that were applied to the participatory methods I used based on Mbuyita (2007):

1. Local people are creative and capable of undertaking their own investigations, analyses and planning.
2. Outsiders (field workers, facilitators, researchers etc.) have a role as facilitators of this process.
3. Local people can and should be empowered to solve their own problems themselves. (p. 177)

So, by using both qualitative community-based participatory research and participatory action research methods, I was able to gain a deeper understanding of the Roma’s

interpretations of their environmental health conditions. They also positioned me to shed light on the environmental health disparities they endure.

Conclusion

The Roma of “Pata Rat” have made headlines in local, national, and international news for over a decade. In addition, numerous social scientists, nonprofit organizations, and anthropologists have made their way through “Pata Rat,” implementing research and development programs. An award-winning documentary was also made starting in 1990 concerning the devastating conditions under which they work and live (Roma National Congress, n.d.); yet their environmental health conditions have not improved. One could argue that one reason for the failure to improve is that in many of these studies and programs there has been an absence of the Roma’s voice. The problem, as I see it, is that the researcher or organizations’ good intentions have been implemented without a deep, contextual understanding of the Roma’s environment.

“The health needs of the Roma population lack visibility, not only because of the absence of research but also the absence of advocacy on their behalf” (Hajoiff & McKee, 2000, p. 868). The Roma of “Pata Rat” need their story told in a way that advocates for their environmental health. More importantly, they need an advocate that is going to co-represent them in a way that includes their voice. To be the environmental health advocate needed for the Roma people, I have chosen to use of a variety of qualitative methods, including ethnographic observation, participatory community mapping, semi-structured/open-ended interviews, and photography, all to engage with the Roma people of Dallas.

Through this methodological approach, I seek to counter the devaluation of the Roma and provide knowledge that will not only better inform future studies and potential solutions, but will also directly address the stigma that is apparent in their present condition. As Brown (2003) asserted, “Qualitative methods are especially important to community environmental health research, as they provide a way to produce community narratives that give voice to individuals and characterize the community in a full and complex fashion” (p. 1789).

Before elaborating on the importance of this qualitative/interpretive methodological research design; Chapter 2 will explore the historical, social, political, and cultural layers of the Roma’s reality that have led to Dallas’ existence today.

CHAPTER 2

REVIEW OF LITERATURE

Background

Emerging from northwest India about a thousand years ago, Gypsies traced a path of legend and romance across Asia and Europe... Within a century most Europeans knew them as vagabond fortune tellers, singers, dancers, beggars, and cunning tricksters (McDowell, 1970, p. 16).

And so one has to wonder: are the Gypsies really nomadic by “nature,” or have they become so because they have never been allowed to stay (Fonseca, 1995, p. 178)?

Around 1000 A.D., the Roma migrated from northeast India to Europe. The precise event that triggered their mass exodus around that time is still unknown; however, possible reasons include a conflict that resulted in their persecution, a natural disaster, or recruitment into a mercenary military. Over the centuries, they divided into tribes and clans, each with its unique traditions, beliefs, and practices, many of which were determined by their occupation and where they settled (Tanner, 2005). The stereotypes of their semi-nomadic ways resulted in persecution throughout history, which were further exacerbated in Eastern Europe. Some even viewed them as descendents of Satan because they believed it was the Roma who had made the nails that crucified Christ (Fonseca, 1996).

Nearly half of all European Gypsies were enslaved from the 1350s until the early 1900s. In the region of Walachia, Romania, Roma were enslaved for over 500 years and used for agricultural labor and treated as property or cattle (Tanner, 2005). Many early and later Romanian historians held the view that Gypsies “wished to become slaves, because this would raise them, if not to the level of human being, at least to a par with

good, domestic animals” (Fonseca, 1995, p. 178). The Gypsies, together with the peasants in the lowest strata of society, were the only ones that could be separated and sold like farm animals. Records of shopping lists and exchange rates were found that included: one Gypsy for one pig, one Gypsy man for garage space, and a team of Gypsies for a team of horses (Fonseca, 1995).

While the Roma in Romania were victims of both slavery and later the Holocaust, they were also victims of stigmatization by Romanian policy. Governments directed their policies towards the Roma as a distinct categorized group and based them on a set of negative value judgments, in other words, a systematic and interlocking framework of stigma. “By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances” (Goffman, 1986, p. 50).

The following comes from part of a decree of 59 rules that were imposed upon the Gypsies in Hungary and Transylvania during the latter half of the eighteenth century. The decree codified prejudice and created the tendency to stereotype leading to the creation of a dehumanization stigma. It was published on October 9, 1783 through the Habsburg program and stated the following (Davies, 2004):

- Gypsies were forbidden to live in tents;
- Gypsies previously under the authority of their voivode [sic] would from now on be under the authority of the village sheriff;
- Gypsy children of four years and over were to be shared out among neighbouring [sic] settlements, at least every other year;

- nomadism was forbidden, and Gypsies already leading a sedentary way of life were permitted to go to market in another area only in cases of necessity and with special authorization [sic];
- Gypsies were forbidden to own horses with the intention of selling them; Gypsy serfs were allowed to own horses, but only for use in agricultural work and they were not allowed to trade in them;
- Gypsies were obliged to adopt the costume and language of the inhabitants of the village in which they are settled;
- use of the Romanes was punishable by twenty-four lashes with a bat;
- the same punishment would be applied to those found eating carcasses;
- Gypsies were forbidden to change their names;
- Gypsy houses were required to be numbered;
- marriage between gypsies was forbidden;
- the local legal authorities would supply monthly reports on the way of life of Gypsies living in their district;
- the number of Gypsy musicians had to be kept to the strictest minimum;
- begging was forbidden;
- it is compulsory for Gypsy children to attend school, with the priest responsible for ensuring their attendance;
- landowners were required to make a parcel of land available to Gypsies in order to ensure their adoption of a sedentary way of life and an agricultural occupation;

- anyone who abandoned their residence or occupation will be treated as a vagrant and returned to their residence. (p. 73)

This decree attempted to assimilate the Roma; however, failed when “Roma moved away in search of places where they would not be forced to give up their way of life” (Tanner, 2005, p. 2). Scholars Lucassen, Willems, and Cottaar (1998) identified four general effects and implications of governments who actively use the stigma in developed policy, as previously demonstrated by rules from the Habsburg Programme in 1783. They are:

- (a) people who are labelled Gypsies are not judged by individual traits but by the (alleged) group traits;
- (b) conjectures and suspicions are enough to keep out, expel and register foreign Gypsies;
- (c) it is difficult for the persons in question to avoid the stigma of being labelled an undesirable alien and potential criminal;
- (d) on the part of the government, much time, attention and money is spent on a relatively small minority group, which is partly a consequence of the prevailing image. (p. 110)

Lucassen et al. (1998) further analyzed stigmatizing effects of government policy and found that the following factors lead to stigmatization:

- (a) Categorizing: the creation of a (group) category with a name.
- (b) The emergence of a negative image which colours perceptions of the category.
- (c) The formation of a negative group characterization, a stigma.
- (d) Labelling: making explicit who belongs to the negatively characterized group.
- (e) Stigmatizing: application, as policy, of the stigma, thus the invocation of negative value judgements [sic], as supporting arguments during the making of policy decisions. (Lucassen et al., 1998, p. 9)

After Romania abolished slavery, some semi-nomadic Roma returned to nomadic ways, while others established themselves in settlements or abandoned buildings, and

some returned to their masters due to lack of opportunity. However, their ostensive freedom did not last long. In 1933 when the Nazi party came into power, laws targeting Gypsies were already in effect and the attitude of the general public was one of mistrust and dislike (Kenrick & Puxon, 1972). The Roma were soon put into Ghettos and concentration camps (Tanner, 2005).

The Holocaust resulted in the mass murder of between 500,000 and 1.5 million Gypsies and was a significant part of the Eugenics movement where the most powerful and educated men were against the vulnerable and helpless. "Eugenicists sought to methodically terminate all the racial and ethnic classes, and social classes, they disliked or feared" (Black, 2003, p. 7). Roma were also repressed and murdered under Stalin's rule in Russia (Tanner, 2005). Research, sterilization, and medical experiments were commonly perpetrated on the Gypsies who were considered of foreign blood in Europe and even referred to as aliens. They were seen as abnormal. Normal was a way to describe the average, the usual, the ordinary, and in some cases the superior race, but instead, the term created an ideal that excluded those who were seen as below average (Baynton, 2001). Race was a major part of this concept of normality. In concentration camps the Roma were targeted and regularly used as guinea pigs for experiments that usually led to death, maiming, and disfigurement. The experiments were generally of no scientific value and at times were just another way of murdering unwanted people (Kenrick & Puxon, 1972). The Roma people call this attempt to exterminate them the Porajmos (Tanner, 2005).

By the time the Communists gained control in 1947, many Roma were already settled; nevertheless, they were still perceived as wanderers (Fonseca, 1995). The Romanian and Hungarian governments tried to force the Roma to adopt a decent 'communist' way of life and settle in major cities (Tanner, 2005). In addition, their horses and carts were confiscated. This was more than just the Roma's means of transportation, but also their source of livelihood (Fonseca, 1995). Nonetheless, life under the communist era was relatively tolerable for the Roma people. They were at least provided access to housing, health care, and jobs (Tanner, 2005).

After the fall of Communism in 1989, the Roma were the first to lose their jobs. With few resources and little education, they could not compete in the new capitalistic society. For example, in 2001, 50% of Romania's Roma were illiterate. Even when Roma were hired, they faced discrimination and were often victims of harassment (Tanner, 2005). Lack of opportunity in the cities led many Roma to migrate outward and form settlements on the peripheries of towns, like Dallas, where they could find a source of livelihood and escape discrimination.

Between the years 1990 to 1995, community violence against the Roma was a part of life in Romania. Rarely, if ever, were non-Roma brought to justice for the attacks, even in cases where Roma were fatally injured or murdered. The earliest episodes of community violence occurred on December 24, 1989, in Turulun in Satu Mare County when two Roma were killed and two houses were destroyed. Over the next five to six years, hundreds of houses in approximately 30 different Roma settlements in Romania were set on fire (Kenrick & Puxon, 1972). It was a way for mobs to apply collective

punishment to Roma communities (CEDIME-SE, 2001) and/or run Roma out of villages.

A survey was implemented in Romania in 1997 by the Centre of Urban and Regional Sociology (CURS) and found “67% of those questioned had an openly anti-Roma attitude while 27% did not care about them at all” (Teichmann, n.d.b).

In the late 1990s, many Roma from Eastern Europe filed asylum claims with the European Union, particularly the UK, Switzerland, Norway, and Canada to escape discrimination and improve their socioeconomic status. Generally, very few Roma received asylum, considering they had come from “safe” countries, and were without sufficient evidence to support their claim. Their claim was based on the 1951 Geneva Convention which says “refugees must have been persecuted or have a well-founded fear of persecution due to race, nationality, religion, political opinions, or members in a particular group” (Tanner, 2005, p. 5). This has not stopped many of them from migrating and trying to immigrate to other European countries.

In Europe, immigration is now on the political agenda. An analysis of the 2002-03 European Social Survey, Sides and Citrin (2007) found respondents in 20 European countries “unenthusiastic about high levels of immigration and typically overestimate the actual number of immigrants living in their country” (p. 477). Before this, Semyonov, Gorodzeisky, and Rajzman (2006) analyzed sentiments towards out-group populations in 12 Western European countries. Results showed a substantial rise in anti-foreigner sentiment between 1988 and 2000 in all 12 countries. These discriminatory attitudes were driven by social, cultural, economic, demographic, political, and psychological contexts. Examples include the impact of changing demographic trends, enduring

national loyalties, and more recently terrorism (Sides & Citrin, 2007). “Contextual changes, such as a dramatic increase in the proportion of immigrants, could launch anti-immigrant sentiment to new heights” (Ceobanu, & Escandell, 2008, p. 1165). “At the individual level, cultural and national identity, economic interests and the level of information about immigration are all important predictors of attitudes” (Sides & Citrin, 2007, p. 477). These anti-Roma attitudes are a consequence of their long history of stigmatization stemmed from the problem of “race” and the stereotypical tendencies to discriminate based on one’s “race.” To this day dislike and fear of the Roma “race” are embedded in the Romanian hegemony and part of the status quo

“Race”

Omi and Winant (1994) argue that many theories of “race” have failed because they have not taken in account the centrality of race as a “fundamental axis of social organization” (p. 13). They point out three paradigms/central categories in race theories where this failure has occurred: ethnicity, class, and nation. A brief analysis of these three theories of race provides substantial insight into the environmental health disparities Roma populations have been forced to endure as a result of their “race.”

Ethnicity-based Paradigm

The Roma have long been defined by others and perceived as a distinct ethnic group. This has resulted in the imposing of stereotypical notions of “common cultural need” on an otherwise heterogeneous group. Groups identified as being culturally different are often assumed to be internally homogeneous (Brah, 2009). This is clearly not the case. Roma are not a homogeneous ethnic/cultural group. There are at least 30

different groups within Romania alone (Teichmann, n.d.a) and they are diverse within their own communities.

Ethnicism tends to define the experiences of racialized groups in cultural terms, and “posits ‘ethnic difference’ as the primary modality which social life is constituted and experienced” (Brah, 2009, p. 506). Viewing the Roma’s situation as one of “ethnic difference” allows people to believe that they choose to live the way they do because of their ethnicity or culture. Although this viewpoint increases understanding, it simultaneously obfuscates the other multi-faceted dimensions that have led to their current situation by limiting the view to “cultural differences.” Moreover, in the communist states of Eastern Europe, “ethnic awareness was equated with ‘wrong’ awareness trying to cover up class differences” (Teichmann, n.d.b).

Class-based Paradigm

The multiple negative perceptions and stereotypes of the Roma by many non-Roma extend beyond their ethnicity. In Dallas and many other Roma scavenging communities, stereotypes overlap with their occupation and low-class status. Generally, the poor and marginalized social groups turn to scavenging/waste picking for everyday survival and income generation. It can be seen as an adaptive response to scarcity by vulnerable populations (Wilson, Velis, & Cheeseman, 2003). Scavenging is not limited to the Roma people of “Pata Rat.” Of the estimated 35,000-50,000 people in Romania involved in scavenging, 80% are Roma. The occupation entails collecting metals, plastics, bottles, and paper from the city’s waste platform and taking it back to their community where it is sorted and packaged. This method causes the accumulation of

residual materials since much of the non-recycled wastes are not transported back (Center for Documentation and Information on Minorities in Europe-Southeast Europe-CEDIME-SE, 2001).

“Due to their daily contact with garbage, waste pickers are usually associated with dirt, disease, squalor, and perceived as a nuisance, a symbol of backwardness, and even as criminals” (Medina, 2005, p. 8). “The attitude of the formal waste management sector to informal recycling is often very negative, regarding it as backward, unhygienic and generally incompatible with a modern waste management system” (Wilson et al., 2003, p. 2006). “The meanings given to these labels, categories, and identities determine whether people will be respected, ignored, or abused” (Schwalbe, 2001, p. 22). Nas and Jaffe (2003) pointed out that in a United Nations Educational, Scientific, Cultural Organization (UNESCO) report “Comparative research and experience have shown that the scavengers consider themselves as a sort of social category associated with “sub-human characteristics” (p. 345).

Nation-based Paradigm

“Roma constitute the largest European minority without a state territory” (Teichmann, n.d.a). They have faced difficulties accessing citizenship because of their social marginalization, living in informal settlements, impoverishment, and widespread racist prejudice from the majority population (Dedic, 2007). Looking at their present conditions from a nation-based perspective, or more accurately from a nationless/stateless-based perspective, their environmental health status in society becomes clearer. Statelessness is a forgotten human rights issue and is “often

accompanied by the deprivation of a host of basic rights and discriminatory treatment, particularly with respect to labour rights, freedom of movement and property rights” (Frelick & Lynch, 2005, p. 23).

The Roma, although stateless and without a nation, have held on to much of their independence to this day. This may be from the long, expensive, and sometimes viewed as impossible, process of obtaining citizenship, or on the other hand, it may be in part from their strategic choices and refusal tactics. Like Africans in the pro-Boer discourses, the Roma have been predominantly portrayed as wronged individuals, rather than citizens of legitimate governments or states (Magubane, 2004). As Magubane (2004) points out, consent played a central role in antiwar suffragists’ political discourse. The Roma, in defense of their independence, chose not to consent to the Romanian government and the powers that have historically refused to acknowledge them as citizens.

It will take decades for these anti-Roma attitudes to change, leading some Roma to migrate to escape continued discrimination or seek better opportunities. Many others; however, will continue to live in isolated segregated settlements and be vulnerable to hazardous environmental conditions.

Vulnerable populations are defined as those individuals or groups who have a greater probability than the population as a whole of being harmed and experiencing an impaired ability of life because of social, environmental, health, or economic conditions of policies. Characteristics of this population include a multiplicity of needs, presence of severe and long term problems, and an unlikelihood of improving their quality of life without assistance. (Biegel & Blum, 1999, p. 1)

In 2003, at a regional conference on Roma, prime ministers and senior government officials from Bulgaria, Croatia, the Czech Republic, Macedonia, Romania, Serbia, Montenegro, and Slovakia announced their plans to launch the Decade of Roma

Inclusion. “The Decade is a political commitment by countries to reduce disparities in key economic and human development outcomes for Roma through implementing policy reforms and programs designed to break the vicious cycle of poverty and exclusion” (Decade for Roma Inclusion, 2005, p. 3). It was officially launched February 2, 2005, in Sofia, Bulgaria and declared for the years 2005-2015. The steering committee, which includes Roma leadership, identified three crosscutting themes: discrimination, gender, and poverty. Each country developed “Decade Action Plans” based on the four priority areas of education, employment, health, and housing. The action plans were developed to complement and reinforce national strategies, not duplicate them (Decade of Roma Inclusion, 2005). At the same conference a consensus was reached that education was the key starting point. The next two sections explore the education and health sectors. From an environmental health perspective it is important to understand these interrelated concepts as they directly affect the environmental health conditions of the Roma.

Education

Studies have stated clearly the role of education as a starting point for providing more opportunities for the Roma and for their inclusion throughout society (Cace et al., 2006). Moreover, educational achievement correlates with economic status more than any other variable (Singham, 1998). The problems Roma children and their families face in school are multi-faceted, complex, and long-standing (Medina et al., 2001). A long history of social problems: distrust, stereotypes, discrimination, and lack of employment opportunities have increased the mistrust of Roma parents in the education system, therefore significantly lowering the perceived value of that education. This lack of value

for education and lack of trust in the educational system on the part of the Roma is a consequence of these deeply rooted social problems and has therefore created a significant achievement gap.

Besides the low value of education in the Roma culture, Roma children face a number of other barriers that inhibit them from succeeding in school and mainstream life. Through previous research and interviews with school staff, students, and parents, the Soros Foundation (2001) identified a series of barriers that Roma children face in the public schools in Eastern and Central Europe. Barriers included:

- Incompatibility between traditional teaching practices and Roma learning styles;
- Quality of teaching in schools with large numbers of Roma;
- Low teacher expectations of Roma students;
- Lack of competency in the majority language by Roma children;
- Lack of academic foundation when Roma children begin school;
- Prejudice against Roma children [on the part of educators, support staff and other children];
- Poverty among Roma families; and
- Perspective and attitudes of Roma parents and children toward public schooling.

(p. 33)

Barriers to education are due to a multitude of causes including economic, cultural, and institutional reasons resulting in differential treatment by educators (Cace et al., 2006). Social and economic factors play a significant role in the lack of education of the Roma population and create a series of barriers. For example, Roma parents may not

have the financial means to dress their children well or buy school supplies. Many parents refuse to send their children to school in old or dirty clothes as those who do go are subject to bullying or feeling alienated from non-Roma children. This discomfort makes them reluctant either to attend initially or maintain attendance. Another barrier is that children are expected to take part in the economic life of the family therefore resulting in high truancy rates. They are often found collecting recyclables, especially in scavenging communities like “Pata Rat.” Also contributing to high absenteeism is physical isolation and poor health (Cace et al., 2006). Lack of access to education is the most pressing problem faced by the Roma people in all respects including:

- pre-school education
- school education (from primary school to high school)
- professional training and retraining
- family education
- civic and religious education
- sanitary education. (Cace et al., 2006, p. 28)

“In current society, formal education complements the role of the family in the socialisation [sic] process of children and teenagers. School has the task of conveying information, skills and values which society considers being important to life” (Cace et al. 2006, p. 27). With Roma children being segregated and only rarely having entered mainstream classrooms, comes a lack of social skills, including communication with Romanian and non-Roma children. The consequence is a higher level of violence and stereotyping for both Roma and non-Roma. This is where educators need to raise their

own awareness and cultural competency regarding the Roma and to teach social and life skills. Moreover, it is crucial that educators encourage communication between Roma and non-Roma children.

When students grow up together, sharing school experiences and activities, they learn to see beyond superficial differences and disabilities and to connect as human beings. This applies to differences in race, religion, economic status, and skill and ability, as well as physical, emotional, and learning differences. It is vital that all students feel safe and welcome in the world, and inclusion provides us with an excellent way to model and insist on a set of beliefs about how people treat one another with respect and dignity. (Sapon-Savin, 1996, p. 39)

Overall, Roma education in Romania is quite poor and after the political change in 1989 it further deteriorated. The decades of forced assimilation and coercion pushed Roma further from their ethnic identity and reduced school performance was a result. The majority of children fail to go beyond primary classes; graduating from secondary and higher education schools is almost impossible, and more than 50% of the population is illiterate. The few exceptions are the Roma elite, also known as the Kalderash (Stanev et al., 2005) who see themselves as representatives of the “real Roma culture” (Teichmann, n.d.a).

Health

“The health status is an important indicator of the quality of life and is determined by the general level of development, consumption patterns, hygiene standards, the level of culture and the quality of public services” (Cace et al., 2006, p. 32). In Romania after 1989, access to health services was at an extremely low level for all Romanians, with Roma communities facing almost a complete lack of medical care. Access to health care

was made even more difficult by the Roma's lack of proper documentation, high health care costs, and additional informal costs (Cace et al., 2006).

The multiple effects of denial of equal opportunities in education – substandard education in racially segregated settings or lack of any education; exclusion from the labour market – denial of jobs to Romani applicants and lack of policies to remedy exclusion; and exclusion of Roma from social safety nets – through direct rejection of Roma and through policies which result in excluding Roma, are responsible for both poor health and lack of access to health care. (European Roma Rights Centre, 2006, p. 10)

In the ERRC's health report accessibility is defined as having four overlapping dimensions: non-discrimination and physical, economic, and information accessibility. These dimensions, introduced in Chapter 1 as being addressed by the UNI Study Abroad Roma Outreach Program, are further articulated as:

- Non-discrimination: health facilities, goods, and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact. For example, investments should not disproportionately favour expensive curative health services, which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population.
- Physical accessibility: health facilities, goods, and services must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups, such as women. Medical services, safe and potable water, and adequate sanitation facilities must also be within safe physical reach in rural areas and for persons with disabilities.

- Economic accessibility: health facilities, goods, and services must be affordable for all. Equity demands that poorer households should not be disproportionately burdened with health expenses as compared to richer households.
- Information accessibility: everyone has the right to seek, receive, and impart information and ideas concerning health issues. (European Roma Rights Centre, 2006, pp. 19-20)

Forms of direct racial discrimination and other forms of abuse to Roma populations in Romania and throughout Europe are still common in the health care system. They create deep rooted exclusion from services and are witnessed through denial of emergency aid, refusal of treatment, segregation, extreme human rights abuse, coercive sterilization, verbal abuse, degrading treatment, absence of medical professionals during delivery, attitudes towards Romani visitors to hospitals, extortion of money, neglect due to language barriers, racial prejudicing, and stereotypes (European Roma Rights Centre, 2006). An example of human rights abuse occurred in February of 2004 in Constanta County, Romania. A 22 year-old Romani mother gave birth to her child via caesarean section. Following the birth she returned to the Constanta County Clinical Hospital for three days requesting assistance when she appeared to be having complications and suffering from an infection. On February 27, 2004, two junior doctors and one doctor removed the women's uterus without consent. Moreover, they failed to inform her of the consequences of the procedure (European Roma Rights Centre, 2006).

Another barrier is physical location. "The health status of the Roma is directly influenced by the location of the community" (Cace et al., 2006, p. 25). For many

segregated and isolated Roma settlements, access to medical services is almost impossible. This is because medical facilities either do not exist or transportation to the facility is either unavailable or unaffordable (European Roma Rights Centre, 2006). Isolated communities in rural areas are those most deprived of medical services and high rates of infection are caused by the lack of hygiene and lack of the most important resources, like drinking water. In addition, many Roma communities are located in polluted areas, therefore exposing them to higher amounts of toxins and higher risk of infection (Arpinte et al., 2002). In these peripherally located communities, uncontrolled dumping of toxic wastes and dirty manufacturing activities are more likely to occur. With squatter communities naturally attracted to these areas due to the availability of, albeit, marginal land, toxic exposures are common with many impacts to health and well being including air quality related respiratory problems, toxics exposure with impacts on many organ systems including the immune system, and poor drinking water and sanitation problems leading to numerous gastrointestinal diseases (C. Zeman, personal communication, February 2010).

Economic status is another barrier to health care for the Roma. Beyond the inability to pay for transportation, services, medications or nutritious foods, they lack the funding and ability to protect themselves from the environment and purchase clean water. This financial disparity and lack of proper hygiene and sanitation therefore reduces access and creates further exclusion. Finally, they lack information about how to live healthy lives, how improve their environmental health, and how to get the documentation they need to access personal and public health services. Communities with health

mediators and educators have been working with Roma populations, but they too need further support, skills, information, and resources, especially in relation to their environmental and occupational health concerns.

To make health services more accessible, the Roma Health Mediator (RHM) program was established. On December 9, 2001 the Minister of the Romania Ministry of Health and Family, the Executive Director of the Roma Center for Social Intervention and Studies (Romani CRISS), and the Adviser on Roma and Sinti Issues for the Organization for Security and Cooperation in Europe and the Office of Democratic Institutions and Human Rights (OSCE / ODIHR) signed an agreement regarding the implementation of a Roma Health Mediator (RHM) system within Roma communities. The collaboration is an integral component of the Romanian government's strategy and was approved by governmental decree no. 430/2001. The program has now become one of the most visible elements of government strategies designed to address Romani health in Romania.

The mediator serves as a bridge for the Roma people to get the information and services they need. Romani CRISS and the Ministry of Health and Family of Romania developed this sanitary mediator role in Romania. Romani CRISS is a non-governmental organization (NGO) committed to defending and promoting the rights of Roma in Romania by providing legal assistance in cases of abuse. In addition, they work to combat and prevent racial discrimination against Roma in all areas of public life, including the fields of education, employment, housing, and health. The RHM's position

description is too extensive to list all responsibilities, but the following provides a general overview of their roles and responsibilities:

- To facilitate communication between the Roma community and the medical personnel;
- To transmit the necessary information to the members of the Roma community regarding the function of the sanitary mediator and the health insurance system;
- To raise awareness of the importance of illness prevention measures;
- Mutual confidence-building between persons from two different worlds, acting as a “bridge” in intercultural relations;
- To respect human rights;
- To cultivate trust between authorities and Roma communities;
- To monitor the local situation of the Roma and to report it to the County Office for Roma. (Elena, Rosin, & Buceanu, 2004, p. 10)

In 2004, Romani CRISS developed a “Guide of Sanitary Mediator.” The guide was intended for training and use by the sanitary mediators as well as the Public Health Directorates to promote better understanding of the roles and responsibilities of the sanitary mediator (Elena et al., 2004). At the time the guide was published there were a total of 109 hired sanitary mediators in 31 counties in Romania (Elena et al., 2004). In 2009, there still had not been a mediator in “Pata Rat” besides the health worker that was employed in 2006 through the RCRC program. To my understanding, there are a number of criteria that a Roma community must meet to qualify for the RHM program; one being there has to be at least 700 Roma in a community. If “Pata Rat” communities are

considered three separate communities, they would not qualify (RCRC, personal communication, May 2007).

With respect to other focus areas in the government's plan, far less is known about health issues that Roma populations face, more specifically in relation to their environment. Despite efforts and progress in both health and education focus areas; little has been done to improve their environmental health conditions. Understanding the link between the Roma's environment and their health aims to further a broad understanding of situational health disparities and aid the government, organizations, and researchers in successfully implementing future health and education strategies.

Environmental Health

The purpose of an environmental health approach is to strengthen a preventive view in public health by thinking of "the environment, the health and the relation between them in an integrated way" (Heller, 1998, p. 11). The environment impacts the health of all humans (Arnesen, 2006). Approximately one fourth of the global burden of disease is due to environmental factors, and of this, children under age five take on 40% of this burden (Pond et al., 2007). Rosen and Imus (2007) argue that environmentally-related diseases have become a public health crisis of historical proportions threatening the health and well-being of children around the world. "Children cannot protect themselves nor can they clean up an environment our society has created. Independently, they have no political or economic voice" (Rosen & Imus, 2007, p. 526).

The effects of childhood exposures to environmental hazards lead to permanent health effects into adulthood. Knowing this, it is important to understand the severity of

early exposure to chemicals. “Early lifetime exposure to environmental stressors can result in death of the developing organism, or lead to reduced birth weight, asthma, neurobehavioral impacts and cancer” (Firestone & Amler, 2003, p. 298). “Young children breathe faster, and eat and drink more in proportion to their body weight as compared to adults. Consequently, children absorb more toxicants contained in air, water or food, which makes them more vulnerable to acute and chronic effects of environmental hazards” (Firestone & Amler, 2003, p. 298). It is also well known that pregnant women are affected differently and disproportionately by environmental hazards (Arnesen, 2006). Breastfeeding infants and children can lead to significant exposures to chemicals; especially kinds that are highly fat soluble, like dioxins and PCBs (Firestone & Amler, 2003). Consequences of hazardous environments to women and children, and to all humans, especially the Roma are an important area of investigation. This investigation into the Roma’s environmental health disparities requires recognition of this problem as an environmental justice issue.

Environmental justice is one of several approaches to environmental and health issues that help to frame the relationship between society and the environment, by focusing “on the relationship between different social groups and the quality of their environment” (Matousek, 2008, p. 68).

Researchers, policy-makers, and advocates concerned about environmental justice argue that communities of color who are segregated in neighborhoods with high levels of poverty and material deprivation are also disproportionately exposed to physical environments that adversely affect their health and well-being. (Morello-Frosch & Lopez, 2006, p. 182)

Racial discrimination tends to be a core issue in environmental injustices. Bullard (as cited in Westra & Wenz, 1995) argued that the geographic distribution of minority and impoverished populations have been “found to be highly correlated to the distribution of air pollution, municipal landfills and incinerators, abandoned toxic waste dumps, lead poisoning in children, and contaminated fish consumption” (p. 7-8). The Roma of Dallas exemplify these injustices, more specifically municipal landfills, toxic waste, lead and chemical poisoning in children, and distribution of air pollution. It will take decades for anti-Roma attitudes to change, meaning many Roma will continue to live in these isolated, segregated settlements that are “disproportionately exposed to environmental hazards and denied access to environmental benefits such as clean air, land, and water” (ERRC, 2006, p. 69).

There are four main patterns of environmental injustice, which are all evident in Dallas. They are (1) exposure to chemicals and hazardous wastes including settlements on or near contaminated sites; (2) higher vulnerability to floods; (3) differentiated access to potable water; and (4) discriminatory waste management practices, (Steger & Filcak, 2008). To change the injustices for Roma settlements and improve their environmental health, environmental policy needs to be advanced and regulated throughout CEE, especially new EU member states like Romania.

In 2001, environmental policy in the European Union focused on 14 key areas: water quality, waste control, air quality, fisheries conservation, general provisions, chemicals, energy conservation, biodiversity, pesticides, noise pollution, genetically modified organisms, forestry, and organic agriculture, (McCormick, 2001). Six major

objectives of environmental policy in Europe were developed from a study from the following three sources (1) the Fifth Environmental Action Programme (EAP); (2) the Environmental DG (EDG); and Article 174 of the treaties. They are:

- (1) Preserving, protecting and improving the quality of the environment (Article 174);
- (2) Protecting human health (Article 174);
- (2) Prudent and rational (or equitable (EDG)) utilization of resources (Article 174), or the maintenance of continued access to natural resources (Fifth EAP), and the preservation of the rights of future generations to a viable environment (EDG);
- (3) Promoting measures at the international level to deal with regional or worldwide environmental problems (Article 174);
- (5) Improvement (or maintenance (Fifth EAP)) of the quality of life (EDG);
- (6) Increased environmental efficiency (EDG)

Later in 2002, the Children's Environment and Health Action Plan for Europe (CEHAPE), was launched at the World Summit on Sustainable Development. Then in 2004, the plan was further developed with a set of indicators at the Fourth Ministerial Conference on Environment and Health in Budapest, Hungary. CEHAPE is to serve as an international instrument for member states to develop and manage indicators of environmental health. The focus is on the future of children and recognizing the importance and need to address their rights, their health, and their particular vulnerability to environmental health risks (Pond et al., 2007).

In an initial investigation of Romania's report for the Approximation of EU Environmental Law, the "Proposal for a Council Directive 93/C212/02, Landfill of Waste" illustrates the insecurity of the Roma of "Pata Rat" in regards to their future and livelihood. Government officials have been threatening to close the municipal landfill where they make their sustenance outside Cluj-Napoca since 1996. It is now scheduled for 2010. It is interesting, however, to point out the level of ambiguity that still exists in this area at the governmental level. The "Proposal of a Council Directive 93/C212/02, Landfill Waste" illustrates this as follows:

It must be pointed out that such detailed way to regard the standardization of waste landfill problem as presented by COM 93/C 212/02, could not be found in domestic legislation. There are some former guidelines, but no legal act comprises the items presented in the proposed Directive. A 'landfill post-care fund' is not provided for by any domestic environmental legal act. Progress in approximating this directive is thus quite poor.

The Roma of Dallas need an environmental health advocate, especially now as their only source of livelihood and "survival," scavenging Rampa, is on the verge of being taken away. The international academic community can assist with their advocacy. This aligns with objective four of European Environmental Policy and Article 174 of the treaties, which is to deal with regional or worldwide environmental problems by promoting measures at the international level.

Since 1989, the academic community has played a significant role in advancing knowledge and understanding of the Roma's reality. By sharing the academic community's accomplishments, much can be learned for future programs and the impact they have on improving the lives of the Roma people. The following analysis provides a

brief background of the role the academic community has played in advancing policy and the Roma's situation.

Role of the Academic Community

“In the communist period, in general, the social problems were largely ignored, hidden under ‘the ideological carpet’ of the party, and, with them, essential domains of academic research such as psychology, sociology and anthropology were also concealed” (Ionescu & Cace, 2006, p. 53). After the fall of Communism in 1989, the academic community released the first “signals of alarm” about the severe social problems that the Roma had inherited from the past. Their recommendations and contributions to the development of public policies were as follows:

- 1) Elaboration of studies and research (some of which are representative at the national level, other studies about local communities, or county and regional analyses), monographs, etc.
- 2) Elaboration of indicators and methodologies for monitoring, evaluating and intervention.
- 3) Elaboration of proposals, recommendations and strategies that underpinned the intervention programs.
- 4) Highly trained and qualified human resources to deal with Roma issues (many persons belonging to the ethnic group) and to understand the real dimensions of the problems that the Roma are confronted with, in order to approach the issues with objective scientific instruments rather than ideological ones, pragmatically rather than emotionally. (Ionescu & Cace, 2006, pp. 53-55)

From the academic community's conclusions and recommendations, three distinct periods of evolution of public policies for the Roma in the Romanian society emerged. The first period, 1990-1995, was called the "period of unstructured search" (Ionescu & Cace, 2006, p. 22). Nonprofit organizations emerged focusing on small urgent problems and their activities were sporadic. Political structures were also set up to defend the Roma and progress was evident in:

- The recognition of the Roma ethnic group in the public discourse, as well as in official documents and policies;
- Political representation provided for in the Election Bill;
- The emergence of Roma activists who were prepared to take on the responsibility of speaking on behalf of the ethnic group on different issues (politics, culture, education). (Ionescu & Cace, 2006, p. 23)

The second period from 1996-2001, known as the period of "understanding responsibilities" was initiated when the Romanian government issued the "Strategy for the Improvement of the Roma Situation in Romania" (Ionescu & Cace, 2006, p. 23). Knowledge of the Roma situation and subsequent interventions significantly increased during this period and a progression of factors contributed to this evolution:

- Reports of the EU Commission that demanded solutions for the Roma situation, including this issue on the list of the political criteria of accession;
- Maturation of the civil society and especially of the Roma civil society;
- Setting-up and development of Government structures that are explicitly responsible for the Roma issue;

- Involvement of international institutions in funding projects for the Roma communities in Romania. (Ionescu & Cace, 2006, p. 23)

Nonetheless, in the 2000 report on the progress Romania had then made towards EU accession, it was stated that the Roma were still commonly discriminated against by the entire Romanian society. Moreover, it was reported that the government had not been involved in solving the problems and the recorded progress was insignificant. The delay in the elaboration of the strategy was the major negative point made in the report; nevertheless, nonprofit organizations continued to grow and reached almost 100 in 2000. The growth of the non-governmental sector led to increased and improved initiatives as well as a more consolidated, pragmatic, and powerful approach to resolving Roma social issues (Ionescu & Cace, 2006).

Finally, the third period, which started in April 2001, began with the elaboration and institutionalization of the “National Strategy for the Improvement of the Roma Situation in Romania:”

The general social-political context in Romania, the preparations to join NATO and the EU, allowed for the reorientation of policies for various categories of the population that were badly affected by the transition to market [*sic*] economy, including the Roma minority. In this context, starting with 1997, the Romania Government paid more attention to the right of national minorities to express themselves, to their organization, but especially to the development and implementation of policies for national minorities in general, and the Roma minority in special. (Ionescu & Cace, 2006, p. 27)

Mediated by international organizations, The National Strategy for the Improvement of the Roma Situation in Romania responds to both general and specific issues of various sectors at the local and national levels. The sectors include “public administration, housing, social security, healthcare, economy, justice and public order,

child protection, education, culture and cults, communication, and civic participation”

(Ionescu & Cace, 2006, p. 24).

Today, research and outreach from the academic community continues to lead to progress in improving the Roma’s situation, more specifically by providing information to organizations, governments, and international initiatives so they can provide more culturally competent and situation-based programs. For both the Decade of Roma Inclusion and The National Strategy for the Improvement of the Roma Situation in Romania, the multi-dimensional approach of environmental health research has implications for deeper understanding of the Roma’s current status. By studying the Roma’s environmental health conditions, the multi-dimensions of the Roma’s historical, political, social, and cultural lived realities are revealed.

Conclusion

“New knowledge concerning vulnerable populations repeatedly stresses the need for a multi-dimensional approach in planning of direct practice and service delivery innovations to meet the multiple needs of target populations” (Biegel & Blum, 1999, p. 2). This review of literature aimed to provide a knowledge base of the historical, social, political, and cultural dimensions influencing the past and present situation of Dallas and Roma populations in Romania, particularly those that have led them to their current poor environmental health status. This historical-socio-cultural-political analysis explored the education and health sectors as a way to exemplify the Roma’s “race” struggles with examples of discrimination, segregation, marginalization, and even direct racism. “Race” issues were further analyzed through Omi and Winant’s (1994) three theories of race

including how the Roma have been perceived within ethnicity, class, and nation-based paradigms. Multiple and intertwining factors have led to the Roma's current state of social and environmental injustice and it will take collaborations between academic, community organizations, governments, and the Roma people themselves to begin to solve their problems.

Chapter 3 continues the discussion on the importance of environmental health research; more specifically research that takes a qualitative/interpretive approach that encompasses participatory methods.

CHAPTER 3

METHODOLOGY AND METHODS

Methodology

Qualitative research methods are used to understand some social phenomena from the perspectives of those involved, to contextualize issues in their particular socio-cultural-political milieu, and sometimes to transform or change social conditions. (Glesne, 2006, p. 4)

A deeply contextualized understanding of the current situation of the Roma in Romania and Central and Eastern Europe is both essential and critical before recommendations for improvement of their environmental health can be made. In two reviews of published literature on Roma health conducted since 2000, it was concluded that there is insufficient data on the health of the Roma and that further research is needed (Hajioff & McKee, 2000; Zeman et al., 2003). Furthermore, it was recommended that future research “be handled with sensitivity by exploring locally sensitive mechanisms and recognizing the social and political context of the society concerned” (Hajioff & McKee, 2000, p. 864).

In Zeman, Depken, and Senchina’s (2003) analysis of 108 articles relating to Roma health, 45% examined genetics, congenital anomalies, and related concerns with these issues. This is also evident in a literature review of 105 Roma studies done by Hajioff and McKee in 2000. Only three of the studies reviewed were conducted on noncommunicable diseases, whereas the others were done on birth defects, reproductive health, and communicable diseases. “What research exists seems to reflect views of the Roma as threats to the majority population, either through infectious disease or their

contribution to the gene pool” (Hajoiff & McKee, 2000, p. 866). What are needed are more qualitative studies to assist the Roma with an understanding of their public, environmental, and occupational health threats (Zeman et al., 2003).

For research studies, the Roma need to be approached as human beings and researchers must take care not to reduce the Roma people’s humanity to data for scientific articles which only advance research careers without having a beneficial impact on the conditions and realities of their subject’s lives. Traditional positivist methodological procedures of gathering information from disempowered populations run the risk of unintentionally devaluing them through scientific reductionism (i.e., the pain of disease becomes a cluster of symptoms or the decimation of a population due to poverty-related illnesses and unmitigated environmental exposures becomes a table of morbidity prevalence and incidence figures). This is not to say that quantitative information is not of value. However, the Roma, at the worst point, have historically been used for scientific medical experimentation, the nature of which continues to provoke well-warranted horror. This history of experimentation reached its nadir during the Holocaust when the Roma were a target for unethical and inhumane medical studies. These studies, among others less horrifying, have provided little to no benefit to them personally. Subsequently, among the Roma people, trust in researchers is low, thus making it increasingly important that this study employ a nonmanipulative research design that makes their interests and well-being of central priority. The use of qualitative methodology and methods is therefore important. As Brown (2003) indicated,

Even when quantitative data are needed to determine the existence of environmental health effects, qualitative data are necessary to understand how people and communities experience and act on these problems, as quantitative data can only render an imperfect or partial picture of health effects and their causes. (p. 1789)

Quantitative and qualitative research are two different ways of knowing and each involves different purposes and processes. Quantitative research is based on the scientific method where a hypothesis is tested using designs understood to be objective and data are statistically analyzed in order to make scientific generalizations. Positivists argue that there is a mind-independent reality “out there” that we can study and come to understand reality “as it really is,” through the use of presumably neutral procedures. This approach operationalizes variables (i.e., defines independent and dependent variables such that they are observable through sense data and quantifiable). In turn, the necessity of operationalizing the variables of interest requires a certain reductionism (scientific reductionism) that removes these variables from the cultural, meaningful, lived context of “research subjects.” The inevitable outcome is research knowledge which does not, because it cannot, account for the complex, the multi-layered, and the historically and social contingent lived experiences of the Roma people (Rorty 1979). That said; the point of this work is not to discount the previous research. It is merely to point out that it is important not to overuse this type of instrumentation and quantification and that one should be cautious of the type of study design, especially when working with a marginalized population like the Roma. Doing so can run the risk of further marginalizing them and deepening their stigma.

This is not to say that qualitative researchers using a post-positivist framework will not use statistical measures or methods in their research. It would, however, be unlikely that the results would be reported as complex statistical findings. Qualitative researchers are seldom, if ever, prone to use inferential statistics. Qualitative research, on the other hand, is based on understanding, interpreting, and representing the participants and their interpretations of their world. Glesne (2006) provides an illustration in Table 1 of the main components of quantitative and qualitative approaches (p. 5).

Table 1

Predispositions of quantitative and qualitative approaches to research

Quantitative Approach	Qualitative Approach
<i>Assumptions</i>	<i>Assumptions</i>
Social facts have an objective reality	Reality is socially constructed
Variables can be identified and relationships measured	Variables are complex, interwoven, and difficult to measure
<i>Research Practices</i>	<i>Research Practices</i>
Generalizability	Contextualization
Causal explanations	Understanding
Prediction	Interpretation
<i>Research Approach</i>	<i>Research Approach</i>
Begins with hypotheses and theory	May result in hypotheses and theory
Uses formal instruments	Researcher as instrument
Experimental	Naturalistic
Deductive	Inductive
Component analysis	Searches for patterns
Seeks the norm	Seeks pluralism, complexity
Reduces data to numerical indices	Makes minor use of numerical indices
Uses abstract language in write-up	Descriptive write-up
<i>Researcher Role</i>	<i>Researcher Role</i>
Detachment	Personal involvement
Objective portrayal	Empathetic understanding

Eisner (1998) suggests six features that characterize a qualitative study and each contributes in their own way to the current study. First, qualitative studies are generally field focused which means they are non-manipulative and tend to study situations and objects intact. This means researchers go out to the location and “observe, interview, record, describe, interpret, and appraise settings as they are” (p. 33).

At this level, qualitative research involves an interpretive naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. (Denzin & Lincoln, 2000, p. 3)

In addition, phenomena are explored in relation to their participant’s social, cultural, political, and physical environments. This holistic approach is characteristic of the interpretivist perspective (Ulin, Robinson, & Tolley, 2005).

Eisner’s second feature of qualitative studies relates the self as an instrument that engages and makes sense of a situation. It provides a way for the researcher to provide personal insight and include their signature. The researcher or self as the instrument forces us to realize that other researchers who interpret the same situation will likely experience and analyze the situation differently, and therefore it is important that researchers analyze why they do things in a particular way (Brown, 2003). Reflexivity is a way to do this and is referred to as “the dynamic process by which new understandings shift our engagement with the world, and how through changing our world, in turn we understand it differently” (Kindon et al., 2007, p. 183). Denzin and Lincoln (2000) point out that the researcher’s gaze will always be filtered through different lenses including gender, social class, race, ethnicity, and language. They also discuss how observations

cannot be objective and that they are socially situated between the realities of-and-between the observer and the observed.

The third characteristic of qualitative research is its interpretive character that within the context of qualitative inquiry has two meanings. The first is that the researcher must “account for what they have given an account of” (Eisner, 1998, p. 35). This is done by incorporating past, current, and future research and images to strengthen descriptions. The second meaning of interpretative character is the experience participants have in the situation in which they are being studied. This is more than simply accounting for their behaviors. Qualitative inquirers go beyond behavioral descriptors by looking at matters of motive and the quality of their experiences.

The fourth feature in qualitative inquiry is “the use of expressive language and presence of voice in text” (Eisner, 1998, p. 36). In qualitative research it is clear that the researcher is the instrument and there is an “I” present in the text. Applying Gadamer’s (Malpas, 2009) ‘fusion of horizons,’ understanding can be seen as involving the formation of a new context of meaning, one that enables integration of what is familiar and what is unfamiliar, alien, or strange. This is done through the process of dialogue in which neither the participant nor the researcher remains unaffected (Malpas, 2009). The concept ‘horizon’ means understanding and interpretation “always occurs within a particular ‘horizon’ that is determined by our historically-determined situatedness” (Malpas, 2009, p. 9). Empathy was an important communication tool that allowed me the ability to identify with and understand the Roma’s situation, feelings, and motives. Through the appropriate use of empathetic communication skills the relationship between

the participants and me was enhanced and I was able to gather information more effectively (Hardee, 2003).

A fifth component of a qualitative study is attention to particulars. Quantitative research focuses on statistical procedures where variables and data have to be created. When numerical data are created in social and cultural contexts a transformation occurs from qualitative to their quantitative “equivalents” for analysis. However through this process, their uniqueness and the flavor of the particular situation are lost and they are no longer equivalent. Qualitative studies can provide that flavor. “Feeling the heat on the seat of one’s pants as one slides down a slope is not at all like reading a gauge that measures velocity and friction. Good qualitative writing helps readers experience the heat – vicariously, of course” (Eisner, 1998, p. 38). Perception is still central, but awareness of the distinctiveness of the situation is required before revelation can occur. “The point is that qualitative studies provide a sense of the uniqueness of the case; the best make the case palpable” (Eisner, 1998, p. 39).

The sixth feature of qualitative inquiry is that the research becomes believable from its coherence, insight, and utility. Ultimately, this has to do with the criteria for judging its success. Unlike the quantitative approach that aims to demonstrate causal relationships through correlations and statistical descriptions of the strength of association, qualitative researchers persuade by reason and by employing multiple representations. The use of multiple sources or evidence helps increase the “weight” and ultimately determine its coherence. “There are always ambiguities, circumstances,

alternative positions, other ways to interpret evidence, and other evidence” (Eisner, 1998, p. 40).

The ultimate test of a quality study is congruence, in other words, how far the research can provide the necessary information, instructions or rules that might enable another researcher to enter and ‘pass’ (i.e. function as an accepted participant) in that setting or group. (Pope & Mays, 2006, p. 39)

“Different kinds of experience lead to different meanings, which, in turn, make different forms of understanding possible” (Eisner, 1993, p. 6). An interpretivist (hermeneutic) approach has the ability to not only capture the Roma’s voice and their perception of their reality, but also further understand the past research that is out there. For example, text interpretation goes back to Biblical times and is concerned with further understanding of Biblical text through what was known about society during that time (Hughes & Sharrock, 2007). To understand the social, cultural, and political dimensions, as Chapter 2 introduced, is to deepen the contextual understanding of past research and the present situation in Dallas. Table 2 illustrates the basic components of positivist, interpretivist, and feminist research approaches (Ulin et al., 2005, p. 16).

Table 2

Three paradigms for public health research

	Positivist	Interpretivist	Feminist
Basic assumptions	The social world is composed of observable facts. Reality is objective, independent of the researcher.	The social world is constructed of symbolic meaning observable in human acts, interactions, and language.	The social world is governed by power relations that influence acts and perceptions. Reality is negotiated and differs according to status and power.
Sources of evidence	Facts are revealed through standard scientific processes and are context-free.	Meanings are derived from perceptions, experiences, and actions in relation to social contexts.	Power, control, and contextual factors can be heard in personal accounts that reflect different versions of reality.
Methods	Pre-structured data collection, controlled measurement, clinical trials are the norm. Examples: surveys, clinical trials, rating scales, structured observation.	Semi-structured, open questions, and observation enable participants to express thoughts and actions in natural ways. Examples: in-depth interviews, focus groups discussions, participant observations, case histories.	Participatory forms of observation and guided conversation enable both marginal and dominant groups to voice opinions and tell their stories. Examples: participatory action techniques, reflexive listening, challenges to political and personal barriers to entrenched positions.
Research intention	Quantitative studies seek explanation, verification, and prediction of human behavior through causal or associative relationships.	Qualitative studies seek discovery, understanding, and insight into the circumstances of human behavior.	Feminist studies seek insight into the influence of gender on human behavior, including differentials in power and control, in an agenda for social change.

(table continues)

	Positivist	Interpretivist	Feminist
Level of participation	Research subjects answer specific, predetermined questions in a structured response format.	Research participants are active partners in data collection and respond to semi-structured questions spontaneously and naturally.	Research participants have relative freedom to direct the data collection process and define follow-up.
Impact on study participants	Impact is neutral. Research subjects may gain new information or insight from the results.	Participants are aware of their engagement in the research process; may gain insight into their own perspectives and behaviors, as well as the research topic.	Participation is empowering. Results may lead to a participant-defined action agenda and empowerment to initiate or participate in policy change.

Ethical Considerations

To ensure the Roma of Dallas understood my purpose for being in their community on a daily basis, YVM/FAF facilitated and translated an introductory session. Following YVM/FAF's weekly Sunday service, staff introduced Dr. Catherine Zeman, advisor of this study, and me, to the Roma people. At that time, Dr. Zeman and I shared the purpose of the study and we introduced the variety of activities that would take place during the coming two weeks. At that time, participants asked questions, were notified that their participation was voluntary, that they could choose to stop at anytime, and finally who they could contact if they had further questions at any time during or even after my time in the community. This informed consent contributed to the empowerment of participants (Glesne, 2006) many of who were excited about the upcoming activities,

especially the photovoice activity, where participants were told they would have the opportunity to take photos of their community.

Typical of qualitative research, I did not always know exactly when or what might emerge, so I was not always in a good position to inform participants with specific details about the research course and what to expect (Eisner, 1998); therefore, to obtain consent for the different research activities, I employed continuous informal renegotiation. This renegotiation was important since respect, interest, and acceptance may have developed or diminished for either the participant or me over time. “This sense of cooperation and partnership may be more relevant to the ethical assessment of qualitative fieldwork than whether or not informed consent forms were signed” (Glesne, 2006, p. 133). As part of this study, I acknowledged that no knowledge is value free (Gallagher, 2008).

The non-realist understanding that there is no value-free inquiry means that researchers construct rather than discover both knowledge and reality. What they know about the social world is not the social world itself but what they make of it...

... Instead they must make careful choices in the absence of complete knowledge, and enter into dialogues (with one another) that offer ethical justifications for actions, choices, and practices. (Gallagher, 2008, p. 913)

Acknowledgment of my prejudices and views of the world and how they may have or have not impacted the construction of the Roma's reality was an important component of the research process. A prejudicial or prejudgmental form of understanding means that we are involved in a dialogue with both our understanding of the issue and of our self-understanding. Gadamer's view of the process of understanding can be seen as coming to an 'agreement' of the matter by negotiation between oneself

and one's partner in the hermeneutical dialogue (Malpas, 2009), in this case the Roma people of Dallas.

In this respect, all interpretation, even of the past, is necessarily 'prejudgmental' in the sense that it is always oriented to present concerns and interests, and it is those present concerns and interests that allow us to enter into the dialogue with the matter at issue. (Malpas, 2009, p. 8)

That said, my primary concern was the environmental health disparities for the Roma people of Dallas. Since, the Roma's environmental conditions were not a setting I had to live in, I needed to engage with them. To do this, I welcomed friendships and encouraged dialogue through conversation and participation.

This study embraced relational ethics, which is based on trust, caring, and a sense of collaboration. This relational framework provided additional opportunities including invitations into people's homes. By using a hospitality lens rather than one of power allowed for care, compassion, and generosity to take place. Glesne (2006) points out specific ways related of being hospitable and acting in a culturally hospitable manner, which I utilized throughout the research process. They are to:

- show "respect for people"
- "present yourself to people face to face"
- "look, listen...speak"
- "share and host people, be generous"
- "be cautious"
- "do not trample over the mana [fundamental duties and rights] of people" and
- "don't flaunt your knowledge." (p. 145)

Ethical issues were considered throughout the research process as well as throughout the process of representation. They were considered first and foremost to the participants. All ethical considerations for this study were addressed by (1) approval from the Institutional Review Board from the University of Northern Iowa, and (2) taking into account the ethical considerations above. According to Wurzbach (2002), my individual behaviors were considered ethical because they: increased trust and cooperative attitudes among people; promoted integrity and honest relationships; enhanced self-respect; did not exploit others; allowed individuals to move toward mutual respect; and dissolved barriers between people.

The first part of this chapter highlighted the different components between quantitative and qualitative research methodologies and pointed out that a qualitative/interpretivist approach was the best suited design for this study. This is primarily because research with the Roma needs to take in account their social, cultural, and political contexts and more importantly include their voice. The next section will continue the discussion of a qualitative/interpretivist approach and introduce the methods that were employed in this study. They are (1) participant observation, (2) semi-structured/open-ended interviews, (3) community participatory mapping, (4) photovoice, and (5) photography.

Methods

Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to self. (Denzin & Lincoln, 2000, p. 3)

Denzin and Lincoln (2000) refer to the qualitative researcher as a bricoleur, a maker of quilts, because of the multiple methods that emerge in a study. There are several types of bricoleurs including narrative, political, theoretical, and interpretive. “The interpretive bricoleur produces a bricolage—that is a pieced together set of representations that are fitted to the specifics of a complex situation” (p. 4). The ultimate purpose is to provide a deeper understanding of the social phenomena under investigation.

Qualitative researchers deploy a wide range of interconnected and interpretive practices, hoping always to get a better understanding of the subject matter at hand. It is understood, however, that each practice makes the world visible in a different way. Hence there is frequently a commitment to using more than one interpretive practice in any study. (Denzin & Lincoln, 2000, p. 4)

In this study, I combined multiple methods to form an interpretive bricolage of the environmental health conditions of Dallas. Methods were chosen because no single method could account for the variations in the Roma’s ongoing human experience. Furthermore, each method provided a different representation of the Roma’s complex situation. To best represent Dallas, I encompassed the many different elements that were going on at the same time including the different voices, perspectives, points of views, and angles of vision (Denzin & Lincoln, 2000). Having a flexible study design and being flexible, which Brown (2003) argues is an important component of qualitative research in

environmental health, was very important because I was dealing with a great deal of ambiguity in the field. “Knowing when it is appropriate to shift gears and when to acknowledge the surprises of observation makes for both good science and good art” (Eisner, 1998, p. 177).

Unlike scientific inquiry, there is no prescriptive set of methods for qualitative research; therefore, the selection of methods was influenced by the imagination and creativity of the researcher. Selection of methods for this study were chosen using the following strategies: (1) to answer the research objective, (2) derived from an investigation of the multitude of ethnographic and community participatory research methodologies, and (3) by the time and resources the researcher had available and could do in the setting. The selected participatory methods addressed the research objectives (1) to identify, describe and portray current environmental health conditions for the Roma of Dallas; (2) to share the voices of an oppressed, marginalized community and population regarding their perceptions of their environmental health conditions; and (3) to contribute to the development of a model for ethnographic and community-based participatory research (CBPR) for segregated and isolated Roma communities. The methods used were (1) observation, (2) semi-structured/open-ended interviews, (3) community mapping, (4) photovoice, and (5) photography.

Participant Observation and Unstructured Interviews

Any gaze is always filtered through the lenses of language, gender, social class, race, and ethnicity. There are no objective observations, only observations socially situated in the worlds of-and between-the observer and observed. (Denzin & Lincoln, 2000, p. 19)

In May 2009, observation took place over the course of 15 days with a total of 13 separate visits and 45 hours spent in “Pata Rat.” A timeline of my major research activities during the 15-day time period is found in Appendix A. I observed throughout the implementation of all methods. As I explored and got acclimated to the community, I kept in mind Berg’s (2004) general aspects of ethnography by (1) taking in the physical setting, (2) developing relationships with community members, (3) observing and asking questions, and (4) locating leaders and subgroups within the community. While at the YVM/FAF Center or in Dallas I observed the Roma people in their daily life. I was like a sponge and took everything in, including the setting, the participants in the setting, both special and daily events, the acts within those events, smells, sounds, interactions, gestures, etc. (Glesne, 2006).

I developed an observation tool with Dr. Zeman found in Appendix B, which I used in both 2008 and 2009 to help with assessing Dallas’ environmental health conditions. I found it very helpful for remembering the different things to look for, especially in 2008 when I was less acclimated to the community. I relied on photography as an illustrative notebook while in the field and took notes after returning home. If there was something I really wanted to write down I would go into a back room in the YVM/FAF Center where I could not be seen. I did this because I did not want to intimidate the Roma or create a barrier if they were illiterate or unable to write. I later

typed up my notes, reread them several times, and organized them by topic areas for analysis. From these categories, I refined them into theories and explanations (Pope & Mays, 2006). On several occasions I wrote reflections over a long dinner.

Through the variety of opportunities for observation I was able to take on multiple roles at varying locations along the participant-observation continuum illustrated in Figure 2 (Glesne, 2006). At times I was a full participant, participating in the YVM/FAF-led programs and activities, and other times I was an observer as a participant, sitting on the front step of the YVM/FAF Center and watching the movement along Pata Rat Road. In addition to observing things around me, I always felt like a participant. I was a participant in their community and in their lived reality. By recognizing my participant status I was able to strengthen the relationships with my fellow Roma participants.

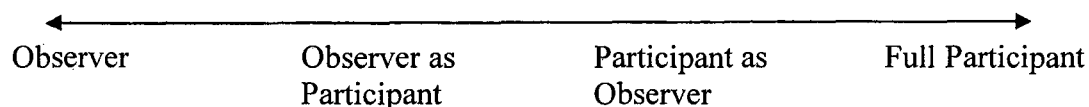


Figure 2. The participant-observation continuum

On many occasions, unstructured interviews and conversation took place simultaneously with participant observation. When I was in the field, I was able to gather a significant amount of data through this informal style of interviewing which sought to understand rather than explain (Fontana & Frey, 1994). Lofland and Lofland (1995) emphasize that the two, participant observation and unstructured interviewing, should be

treated equally as central techniques in naturalistic investigation. I used both these methods to discover the participants' experience of the topics under investigation. Topic areas for discussions and conversations were outlined prior to my arrival to assist in anticipating situations and opportunities during the study. They included water (drinking, use, wastewater, continuity); solid waste management; latrine use; health and quality of life; and animals and vectors. Table 3 indicates general to more specific questions that were asked during interviews, conversations, or identified through observation.

Table 3

Questions for interviews, conversations, and observation

Health and Quality of Life

- What is the health problem that is of greatest concern to you at the moment? Of your children's? Of your community?
- Have you been sick in the last month?
- If so, what were your symptoms?
- What did you do?
- Has your child been sick in the last month? If so, what were his/her symptoms? What did you do for him/her?
- In the last year, how many times were you sick? Your children?
- What kinds of illnesses or symptoms did you have?
- When you or your child has a stomach ache, what do you do?
- Do you use home remedies?
- Can you please tell me some things that you like most about your community?
- Can you please tell me about things in your community that you believe improve your health? Your quality of life?
- Are there things in your community that you think may have made you ill? Your children ill?
- Can you please describe them or tell me about them?
- Are there any things about your community you would like to change?
- If so, please tell me about them?
- Do you think these things can be changed? Do you have any ideas or suggestions on how?

(table continues)

- Where would you like to see yourself in 5 years?
- Do you imagine yourself here in Pata Rat?
- How do you imagine this community? Is it the same or different? Please describe it.
- How do you envision the future for your children?

Water Use

- Where do you collect your water? Do you collect all your water there? For all uses?
- What is the most important use for water?
- Who collects the water? What do they collect it in?
- Do you transfer the water to another container for storage?
- What do you store your drinking water in?
- Does your drinking water ever make you sick? Your children?
- What do you think of the water (taste, quality, distance, color)?
- What do you do with the water after washing? Clothes? Latrine? Bathing? Cooking?
- What do you think about the puddles of water in your community?
- Do you think it affects your health or how you feel? Your children?
- Where do you wash your clothes?
- What do you wash your clothes with?
- If with soap, where does the soap come from?
- Do you think that the water you use affects your health? If so, in a good or bad way? Why or why not?

Latrine Use

- Where do you go to the bathroom at? Do you use a latrine? Do your children use the latrine? If not, where do you/they go?
- Do young children wash their hands after using the latrine? Do adults wash their hands after using the latrine?
- Is there a hand washing station near where you go to the bathroom? Would you use one if there was?
- Do you have a latrine? If so, who made it? Who cleans, repairs, empties the latrine?
- How do you find the latrines (structure, cleanliness, privacy, smell)?
- Do you use the latrine at night? If not, what do you do?
- Do young children use the latrines? From what age do children start to use the latrine?
- What happens to the stools of young babies?
- If you don't have a latrine, why not? Do you want one?
- Do you think that latrine use and washing hands contribute to good or poor health? If so, why or why not?

(table continues)

Animals & Vectors

- Do you have problems with bugs? Rats? Other animals? (bites, annoying, quantity)
- What kinds of animals? How do you contain them?
- Do you have problems with bugs/rats or other animals inside your home? Outside your home? Please tell me about them.
- Do you think that problems with bugs, rats or animals could be contributing to good or poor health? If so, why or why not?

Solid Waste Management

- Where do you dispose of household waste? (e.g. cooking, cleaning, working)
 - What do you do with your leftover waste that cannot be recycled?
 - Do you think that leftover waste in your community could be contributing to good or poor health? If so, why or why not?
-

Semi-Structured/Open-Ended Interviews

Semi-structured and open-ended interviews also took place over four separate afternoons in 31 Roma households in Dallas. The questions were adapted from the topic areas outlined above and made into a short questionnaire. Appendix C provides an English version of the questionnaire and Appendix D provides the translated Romanian version that was used in the field. The purpose of the questionnaire was to assist the YVM/FAF volunteers and translators with interviews and conversations. It served as a guide that helped facilitate discussion (see Figure 3) where many times additional conversations took place. Before going out in the field I reviewed the questionnaire with YVM/FAF volunteers to make sure they understood the questions and the purpose of the activity.



Figure 3. Semi-structured interview in Roma household

I personally accompanied three of the four interviewers during their sessions and participated in 15 interviews. For those that I participated in, the interviewer translated their answers so we were all participating in the conversation. At times, both the interviewer and I asked additional questions that were not on the questionnaire. Answers were noted on the questionnaire itself or written down after leaving the community. Participants were selected by walking through the community, but were limited to the family members who were at home during the times we were in the field. Households from varying socioeconomic levels took part including participants living in shacks, wood-frame houses, and concrete homes. Men, women, adolescents/young adults, and the elderly participated in this activity.

On several occasions, more than one family member was present and participated in the interview/conversation. At times, this strengthened the interviews, as answers were openly discussed among family members and included input from more than one person in each household. At other times, however, this limited the conversation. For

example, when only one family member was present or when family members disagreed, only the dominant view was included. No one refused participation, and many invited us to their homes. For example, during one interview a neighbor listened in and afterwards led us back to her home where we talked with her, her husband, and her 12 year-old son. Along the way, I distributed toothbrushes to participants. In addition, I took family photos, which I distributed on my last day. Discussions ranged anywhere from 20 minutes to one hour depending on the interviewer and the extent to which additional discussion took place. After the house visits, the interviewers and I discussed the results and conversations they had with their participants. Volunteers stated they had enjoyed the experience and learned more about the people and community with whom they work. An YVM/FAF volunteer assisted in translating the documents and going over any questions or clarifications.

Community Mapping

Community mapping is an "eye opener" to the wider issues affecting the community. (Glockner, Mkanga, & Ndezi, 2004, p. 197)

Community mapping, also known as participatory mapping (PM), is seen as a tool of empowerment. Its roots are in participant observation and collaborative research methodologies and have ties with social action and justice (Herlihy & Knapp, 2003). There were several advantages of selecting participants for the mapping activities that aligned with those of focus groups (Pope & Mays, 2006):

- They did not discriminate against people who cannot read or write.
- They encouraged participation from those who may have been reluctant to be interviewed on their own (i.e., intimidated by the formality and/or isolation of a one-to-one activity), and
- They encouraged contributions from people who may have felt they had nothing to say or who could be deemed ‘unresponsive’ (but who can engage in discussion generated by other participants). (p. 26)

Two different mapping activities representing two different subgroups of Dallas took place over three separate sessions. To assist with the implementation of the community mapping activity, a brief activity description was developed and shared with YVM/FAF volunteers. The description, found in Appendix E, pointed out the main objectives for the activity and helped guide facilitation. For the first map, I arrived early with two volunteers from YVM/FAF to prepare the area, which had been chosen the day before when I went to the YVM/FAF’s Sunday service. We started by sweeping the black dirt area and making piles of a variety of materials for participants to choose from. Items included rocks of different sizes, insulation tubing, plastic bottles, sticks, and other debris. YVM/FAF volunteers helped facilitate and translate the mapping activity, where people were told to make a map of their community, the bathrooms, and water sources. Men, women, and children (see Figure 4) participated in the activity, which took place on an early Monday evening across the street from Dallas.



Figure 4. Community mapping activity with community leaders

Mapping took about an hour to complete, two and half hours if you add in the preparation, recruitment, and friendly conversation afterwards. Participants were recruited with the assistance of a young Roma woman that lives in Dallas and works with FAF. The activity provided an important participatory opportunity to gain the trust of local leaders at the onset of the study, which was helpful during the rest of the research process. It not only engaged participants and gave them time to reflect on their situation, but it also led to increased participation in other activities, in which they were more willing to share information (Almedon, Blumenthal, & Manderson, 1997). Mapping is also an “eye opener” to wider issues affecting communities (Glockner, Mkanga, & Ndezi, 2004) and the most valuable part of this method lies in the analysis of the discussion that takes place during the activity (Almedon et al., 1997).

The green building in the background of Figure 4 is the YVM/FAF’s New Life Education Center and is where community members go for spiritual, health, and

education services. The organization serves all of “Pata Rat,” but the vast majority of their participants are from Dallas. I have participated in a variety of the YVM/FAF’s programs where you can expect to see many Roma community member members, sometimes even more than a hundred.

A second mapping activity (Figure 5) took place in the YVM/FAF New Life Education Center with 18 youth, ages 12-17. The original map was made using pencils on a long piece of a light cream construction-like paper that measured approximately 2 x 6 feet (1.10 x 5.9). YVM/FAF staff assisted in facilitating the activity and provided translation throughout the activity.



Figure 5. Community mapping activity with YVM/FAF Roma youth group

Participants worked on the map for approximately 45 minutes and an additional 20 minutes during a follow-up session the week later. Youth revisited the map a second time to see if they wanted to add or change anything. At this time, they added more details including garbage trucks, piles of recyclables, and footpaths.

For those involved in the mapping activities, friendships were made and trust and mutual respect were strengthened throughout the entire research process. More importantly, the maps they made provide a starting point for recognizing Dallas and its existence as a community. Furthermore, they are representations of their community through their eyes. Insight gained from the mapping activities will be explored in Chapter 4.

Photovoice

Only through allowing ourselves to be open to understanding another individual's way of making meaning and interpreting the world can we grow and be perceptive to the assets and needs of those we serve. (Molloy, 2007, p. 52)

To gain an understanding of the community through the eyes of the Roma that live there, I employed the PAR technique of photovoice. “The technique entrusts cameras in the hands of community members, with the acknowledgment that their perspectives are valuable and necessary to the understanding of a particular problem or event” (Molloy, 2007, p. 41). Most often, photovoice participants, like the Roma of Dallas, are the ones who have previously been the subjects of professionals’ and researchers’ photographs (Wang & Redwood-Jones, 2001). The activity provided an opportunity for them to be the photographers and me an opportunity to learn from them and support them in a way that respects and values their position in society (Molloy, 2007). Essentially, there were three main goals for using photovoice as a PAR strategy (Berg, 2004). They were to:

1. Empower and enable participants to reflect on their personal and community concerns.
2. Encourage a dialogue about personal and community issues through discussions about photographs.
3. Access the perception of those not in control of various issues and share that information with those who are in control (policy makers, politicians, health professionals, educators, etc.). (p. 205)

Four separate photovoice activities were implemented. The first was during a community walk-through with a 17-year-old male. I showed him how to use my digital camera and he took pictures of the water sources during our walk. At the first water source, he even crawled down inside the well and took pictures. Personally going inside the well to take pictures was not something I had thought of and I do not know that if I had thought of it, I would have done it. This activity provided close-up images of waste inside their most frequently used water source that would have otherwise not been captured. Though his participation and his unique perspective, I was able to get more information than I would have by myself.

The second photovoice activity was implemented with another 17-year-old male. With the help of a YVM/FAF staff member, I showed him how to use a disposable camera and asked him to take pictures of a typical day's work at Rampa. It was a Thursday afternoon and there was a light sprinkle outside. The light rain actually worked out well for the images because the amount of dust was minimized. Other days when it is really dry, the Roma can get lost in the dust behind the garbage trucks that are coming

and going. All pictures of Rampa included in this study, except the entrance, were taken by the Roma adolescent who participated in this activity.

The third photovoice activity was implemented with 14 Roma youth from the YVM/FAF weekly youth group. This was done after the follow-up mapping activity and eating mici, a Romanian sausage that I brought for them. They split into four groups. Each group had a couple different cameras including 35mm cameras with film, disposable cameras, and a digital camera. YVM/FAF staff members assisted with facilitation and translation needed for the activity. For a short hour, the Roma took pictures of Dallas focusing on both the physical and built environment. In addition, they took a lot of pictures of their family and friends, many who posed and smiled along the way.

I personally went with the group of four females that included three Roma, one Romanian, and me; however, I also intersected with the other groups in Dallas during the activity. For example, at one point I encountered one group and helped them change their film. Within my group, the three Roma females took turns taking pictures with my digital camera while the Romanian girl helped in translating along the way. She participates in the weekly youth group where YVM/FAF staff picks her up in Cluj on their way to “Pata Rat.”

When we started the activity it was sprinkling. Everyone was excited and started out with a fast walk, taking lots of pictures. We went inside homes, the girls posed in front of the water wells, and we visited with people along the way. About mid-way through the community, the rain started to pick up and so did our pace. We stopped in a

home where family members posed with cigarettes dangling from their mouths. From there we went toward the pigs' dwelling where we ran into a young man feeding them two buckets of a soaked bread mixture. We continued on and went to one of the girls' homes. Her father runs one of the local markets. He was with a customer and they preferred not to have their picture taken so we left. Within a few more minutes the sprinkle had turned into a heavier rain, very close to a downpour, and we had to take cover inside people's homes and under awnings. As we ran, we were slipping and sliding through the mud and waste. Community members posed for us as we ran by. Everyone was having a lot of fun and the rain really did not bother us. My camera had to be wiped off several times and the Romanian helped instruct them to keep the camera hidden when we were out in the rain.

Finally, two groups of us ended up near the collection center taking pictures of a few adolescents hanging out and smoking. I was across the street from the collection center, ready to cross the street, when a garbage truck was fast approaching. I felt a sort of "uh-oh" feeling. I had nowhere to go and there were massive puddles along the road. All I could do was turn around, stuff my camera down my pants, and run into Dallas. Unfortunately, I was not quick enough. When the truck passed, a tidal wave of water literally splashed over my head and I yelled "Oh My Goodness!" The wave came from the large puddles that had been in just the right spot from where I was standing. Completely drenched, I turned around to the collection center to see everyone laughing hysterically. I laughed with them, crossed the street like a wet cat, and we had a very bonding moment. We took photos of each other and hung out in the rain. When my

camera's display started to look like it was raining on the inside, we had to bring the activity to a close. Although the activity did not go as I had imagined and the weather did not cooperate, it was successful. Everyone took a lot of great photos and more importantly, we all had a lot of fun. Everyone met back in the YVM/FAF New Life Education Center; we took a group photo, and dried off.

The fourth and final photovoice activity was a follow-up session held the day after the large group session. It was the middle of the afternoon on Friday and was quite gloomy and raining. Only five participants from the night before participated; however, those who did selected pictures to give to the others who were absent. Before their arrival I set up a table with a variety of materials for them to use including cardstock, small photo albums, scissors, glue, tape, note-cards, pens, and rulers. During the activity (Figure 6), participants organized the photos by putting them into small albums. It was their preferred method for displaying their work. Two participants took a couple photos, taped note cards on the back, and wrote captions for the pictures. Participants were allowed to keep the pictures they wanted and distribute others to their friends and family whom they had taken pictures of. After all the photovoice activities, I gave two 35mm cameras and several rolls of film to the YVM/FAF Youth Directors to use for future activities.



Figure 6. Follow-up photovoice activity with YVM/FAF Roma youth group

For future photovoice activities, I recommend having both disposable and digital cameras for each group. The 35mm cameras were more difficult to work with and harder to learn how to use in such a short amount of time. In addition, several rolls of film only partially turned out and two did not turn out at all.

Photography

What we seek are new ways with which to interpret the world, ways that make vivid realities that would otherwise go unknown. (Eisner, 2008, p. 11)

Photography proved to be a very important method that enabled me to gather more data than I would have been able to gather otherwise. Photographs served as an illustrative notebook for me while I was in the field (Pink, Kurti, & Afonso, 2004). The Roma have a high rate of illiteracy, and even for those who are literate, having someone write notes about you is intimidating and can affect how that person behaves. Photographs not only captured the Roma's lived reality in a very non-manipulative way, but they also provided me a way to get consent.

Before I took pictures I asked participants for permission, sometimes verbally but most often through cross-cultural gestures, especially since sometimes we were far enough away that we would have had to yell. Through these gestures I was able to ask permission and participants were able to demonstrate their consent. On many occasions, people wanted me to take additional pictures. They invited me inside their homes to take pictures of their families and friends, while others would pose in different places throughout the community. I did not mind following them to where they wanted to have their picture taken, and sometimes I even helped them find a good spot because of the sun. It was fun being their photographer and also letting them determine how they wanted their picture taken. On the last day of the research study I distributed over 250 pictures to community members, some even received pictures from the year before. Rarely did people refuse to have their picture taken. If they did it was generally because they were dirty from working at Rampa or playing in solid waste. Most times, they were happy to have their picture taken.

Photographs were analyzed by sorting, organizing, and categorizing them into different environmental health conditions. They included, but were not limited to: (1) solid waste management; (2) management of water sources or broken water sources; (3) the sanitation of and proximity of latrines to water sources; (4) the location of animal's living quarters and their proximity to water sources; (5) hygiene and sanitation practices, particularly among women and children; and (6) vector-borne diseases.

Although photographs are seldom used in research, Eisner (1998) points out that they "can be a very useful way for displaying what a situation is like" (p. 187). They

should be viewed as an equally meaningful element of ethnographic work and incorporated where appropriate or enlightening to do so (Pink, 2007). “Photographs and films can say things that not only would require pages and pages of words to describe, but in the end could not be adequately described with words” (Eisner, 1998, p. 187). “The neglect of such potentially powerful resources is due to habit, custom, old norms, and limited views of the nature of knowledge” (Eisner, 1998, p. 188). Weber (2008) points out 10 good reasons to use visual images in research:

1. Images can be used to capture the ineffable, the hard-to-put-into-words.
2. Images can make us pay attention to things in new ways.
3. Images are likely to be memorable.
4. Images can be used to communicate more holistically, incorporating multiple layers, and evoking stories or questions.
5. Images can enhance empathic understanding and generalizability.
6. Through metaphor and symbol, artistic images can carry theory elegantly and eloquently.
7. Images encourage embodied knowledge.
8. Images can be more accessible than most forms of academic discourse.
9. Images can facilitate reflexivity in research design.
10. Images provoke action for social justice. (pp. 44-46)

All the images in chapter four are a combination of photographs taken by photovoice participants and myself. Although we are not professional photographers, the photographs are still able to construct and represent reality (Pink et al., 2004). Images

from nonprofessionals can even be more convincing and more true to life with their not-always-technically-perfect images (Weber, 2008). Without the use of photographs I do not feel the lived reality of the Roma's environmental health conditions could adequately be portrayed. Words alone cannot provide the level of understanding needed to begin to address the Roma's environmental health disparities.

Using photography and visual images in the design and presentation of this study has led to an arts-informed qualitative research approach. In other words, art has had an influence on this study design and representation of the Roma's lived reality. "The central purposes of arts-informed research are to enhance understanding of the human condition through alternative (to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible" (Cole, & Knowles, 2008, p. 59). Art contributes to knowledge by (1) addressing qualitative nuances of situations, (2) generating a kind of empathy that makes action possible, and (3) it provides a fresh perspective so that old habits and ways of thinking do not dominate the field (Eisner, 2008).

Conclusion

This chapter emphasized the importance of using a qualitative/interpretivist methodological approach as the best suited design for this study and for working with Roma and marginalized populations and discussed the multiple participatory methods that were employed. Through analysis and interpretation of observation notes, household questionnaires, maps, and photographs I have been able to construct meaning by constantly moving back and forth from the parts and the whole and from the multiple

data sources. Smith (1989) points out that this constant movement is required for achieving interpretation.

It was through this movement that I made meanings. By moving back and forth in the narrow sense, the Roma individual and the Dallas community, to the wider sense of environmental health issues for Roma, marginalized, and scavenging communities across CEE and the world, I positioned myself to share a multi-layered version of the Roma's lived reality from an environmental health perspective. More significantly, a version that accounts for the historical, political, cultural, and social dimensions that have led to their current place in society, or perhaps more literally said, their place outside or on the perimeters of society.

In the next chapter I will take you on a short journey through Dallas and visit the Roma working in Rampa. Your journey will be presented with intertwining narrative, images, and categorical knowledge. The purpose is for you to gain a more nuanced understanding of the Roma of Dallas' lived reality, more specifically of their environmental and occupational health disparities. An added dimension of this approach is its potential to share the voices of the Roma people, who all too often have gone unheard.

CHAPTER 4

DALLAS

If we are sociologically mindful, we will look for alternative images, accounts, and representations and try to create our own picture of things-of people, places, events, history, groups, and so on-rather than accepting the pictures that are handed to us. Only by doing this can we find out if there are alternative versions of reality and if those versions have been suppressed. (Schwalbe, 2001, pp. 150-151)

To better understand the Roma of Dallas' lived reality one must experience that reality and the best way to do this is to actually go there and learn how they see the world. Since it is not possible for you to physically go there at this time, I will take you there with your mind (Schwalbe, 2001). In this chapter, I will take you on a mental journey to Dallas and introduce you to the Roma people who live there. Through narrative, maps, and photographs your mind will be have access to a deeper level of understanding of the environmental health disparities the Roma endure and how they view and perceive the world.

Your journey provides one version of their reality, one that is co-presented by the Dallas people and me. Since many times "groups unequal in power are correspondingly unequal in their ability to make their standpoint known to themselves and others" (Collins, 2009, p. 465), I will be presenting on their behalf. My aim is to present Dallas as a shared experience, where community members have shared with me, and now 'we' are sharing with you. This version emphasizes the conditions in their environment that are affecting their health and well-being. From an environmental health perspective, I will narrate through multiple, interlocking lenses including a qualitative/interpretivist, community-based participatory action researcher, environmental sociologist, a visual

ethnographer/photographer, and finally a friend to the Roma people of Dallas. In addition, I will move back and forth between wide and narrow foci to better illustrate the Roma's position within a larger context. The goal is to highlight their perception of reality and not allow it to become further abstracted.

This style of presentation has the ability to connect people, build trust, and strengthen relationships with marginalized communities (Lucassen et al., 1998). Pitt as cited in Lucassen et al., (1998) points out that "at the structural level of change, storytelling has the potential to uncover knowledge that has been subjugated to dominant ideas, particularly when groups at the economic or cultural margins engage in a shared process of storytelling" (p. 36). Rather than tell the Roma of Dallas' story from the perspective of statistics and tests of significance I chose to make friends with my research participants, and to get to know them along with their daily lives and struggles.

Before you embark on this journey, I will share demographic information and show you maps community members made of their community. From there we will observe daily life and movement along Pata Rat Road followed by a short walk through the Dallas community. Along the way I will point out identified environmental health concerns. After our walk, we will visit Rampa, the municipal landfill where the vast majority of community members work. Finally, we will discuss identified health concerns and the environmental health disparities they have been forced to endure.

Demographics

In Romania, after the communist regime fell in 1989, many Roma migrated to “Pata Rat” to escape discrimination, but more importantly to find work at the municipal landfill. From a local survey of 31 of 105 total households or just under 30% (0.295) of the Dallas community, 29 or almost 94% (0.935) of those who responded have lived in Dallas for five or more years. Although the question was to be limited to five or more years, many people shared the number of years they have lived in Dallas, 42% (0.419) or 12 households responded with answers ranging from 15-20 years. In this same survey 29 households or 94% (0.935) migrated from towns and villages from Cluj County.

Looking at Roma migration from the Porajmos (Holocaust) to the present, Joshua Benjamin (2008) points out three parts of their migratory tendencies: (1) the historical aspect including the background of the Roma tradition in Europe, (2) the role of ethnic and political persecution, and (3) the tendencies to migrate for economic reasons. These three tendencies influenced “Pata Rat’s” existence, more specifically tendencies for economic reasons. In conversations, local Roma expressed they would stay in Dallas as long as there was work. If, or more accurately stated, when the municipal landfill closes, the Roma will lose their means of “survival,” thus they will be forced to relocate and migrate to where they can find employment.

Dallas is continuously changing and developing, especially their built environment which has made significant developments in the last couple of years including the building of more homes, recycling co-ops, a collection center, a bar/restaurant, and markets. On the other hand, houses have also been torn or burned

down, water sources have broken, and latrines have moved. In order to find this out and gain a better idea of the population within Dallas, I ventured out on a community walk-through. With the help of a 17-year old Roma adolescent and a volunteer from YVM/FAF we counted 105 homes: 22 latrines, 15 animal living quarters, 3 wood houses, 2 garages, and 2 storage sheds. The animal living quarters were home to mostly horses, while 2 were home to pigs, and 1 large dwelling was home to sheep and/or cows.

Using results from my community-walk through and the household surveys it is estimated there are between 550 and 600 Roma living in Dallas. From the household surveys, there were 169 people living in 31 houses: 45 adult males; 40 adult females; 8 youth ages 13 and older; 24 children ages 6-12; and 52 children under the age of five. These demographics point out, at least among those who were surveyed, that the highest populated subgroup are children under the age of 5, who are the most vulnerable population to environmental hazards. If the same average of people per household (5.45) reflects all of Dallas, then a more proximate population estimate would be 572 with 252 children under the age of 12, and 176 of those children under the age of five.

Even though Dallas has existed for approximately 15-20 years, the community does not exist on the map. It is an 'invisible' community that when viewed through the free, global, geographical information tool Google Earth, mysteriously clouds over providing no insights to the nature of the community via satellite. To recognize the community's existence and put them "on the map" I will share a couple maps made by community members.

Figure 7 is an image of the finished rock map made by men, women, and youth. The map covers the area from the YVM/FAF buildings (blue arrow, bottom left) and bar/restaurant (green arrow, represented by 3 stacked rocks across from YVM/FAF buildings) down Pata Rat Road to the collection center (red arrow, bottom right). Community members used rocks to create an organized layout of Dallas and represent their community with a developed built environment. Included in the built environment are roads/intersections, houses, water sources, a public restroom, a church/health clinic, a bar/restaurant, and a collection center. Of the variety of materials available for making the map, participants only used the rocks. They did not use the other recyclables, sticks, and debris that were provided. They want people to see Dallas as a community, not as a waste pile, landfill, or dump.



Figure 7. Rock map made by community leaders

Participants started their map by identifying three main intersections, which they consider the primary paths in the community. Two of the paths are more developed with rows of houses lining both sides of the roads and you can see the paths drawn out in the dirt. They used these paths/roads as a framework on which to build their map. Attention to their built environment was further illustrated by the inclusion and/or exclusion of latrines and water sources. Broken water sources were not included on the map because they no longer function and are not useful. Latrines were also not mapped. The only bathroom that was included was the YVM/FAF public restroom/shower. Mapped houses consisted primarily of the built concrete-houses rather than the many shacks and wood-built homes; however, exclusion of these houses was influenced by the lack of additional rocks available for the activity.

A transcribed version of the rock map, illustrated in Figure 8, is a scanned version of the original transcription drawn by a YVM/FAF volunteer. The circles represent the shacks and are labeled as tents and the squares are the built houses. The circles of small circles represent the wells and finally the YVM/FAF public shower/restroom facility is represented as a rectangle with circles around it. Not included in the legend, but included on both the rock and transcribed maps are the YVM/FAF New Life Education Center, the bar/restaurant, and the collection center. The road going alongside the community is Pata Rat Road.

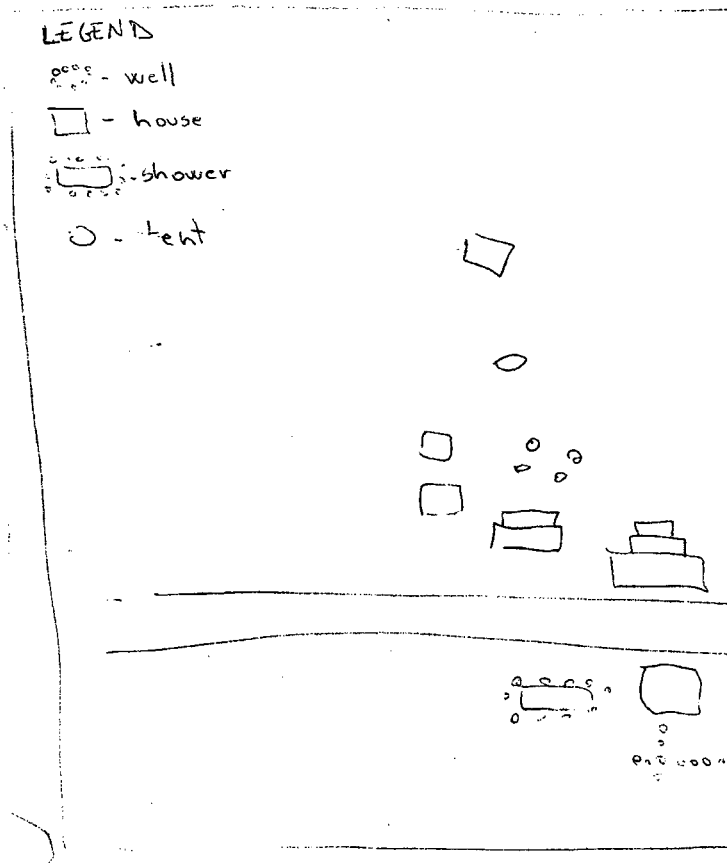
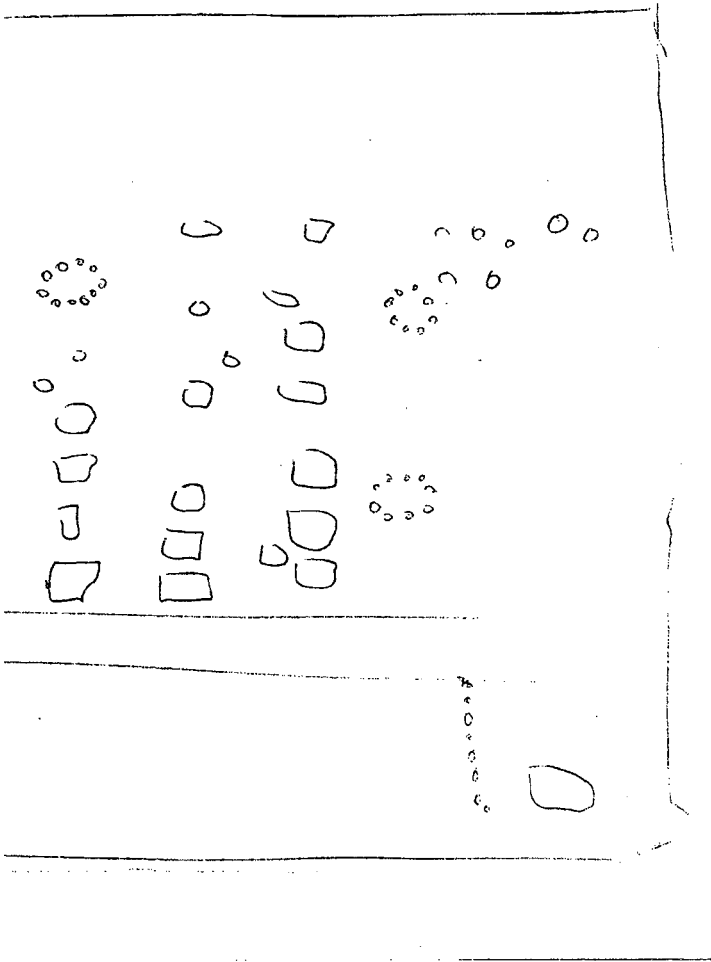


Figure 8. Transcribed rock map of Dallas



The next map, (Figure 9), made by 16 Roma youth, provides another cartographic representation of the Dallas community. It is a more detailed version than the first map with respect to the type of materials used. Additional details identified in this version, that again emphasized the built environment, are the inclusion of a garage, a recycling co-op, a place that gives loans and buys recyclables, a market, the public area where many go to defecate, and a couple of the animal dwellings including the one near the second functioning water well. Participants included all five of the original water sources, even if they are no longer functioning. Because of the way they started and the size of the paper, the map does not include many of the homes located in the area behind the bar/restaurant. The bottom left of the map is the bar/restaurant where both Roma community members and non-Roma working in the area are frequent patrons. Many stop for lunch on their way to or from Rampa or to grab ice cream, soda, beer, or cigarettes. Many of the participants drew their own homes and drew them larger than the other homes, some with black roofs and others labeled with their names. This was a way for them to show where the center of their world is.

Similar to how community members chose not to use available recyclables/debris when making the first map, the youth collectively decided not to include the garbage and solid waste piles. They, too, want to be viewed as people living in a community and not seen as people living and working among garbage.

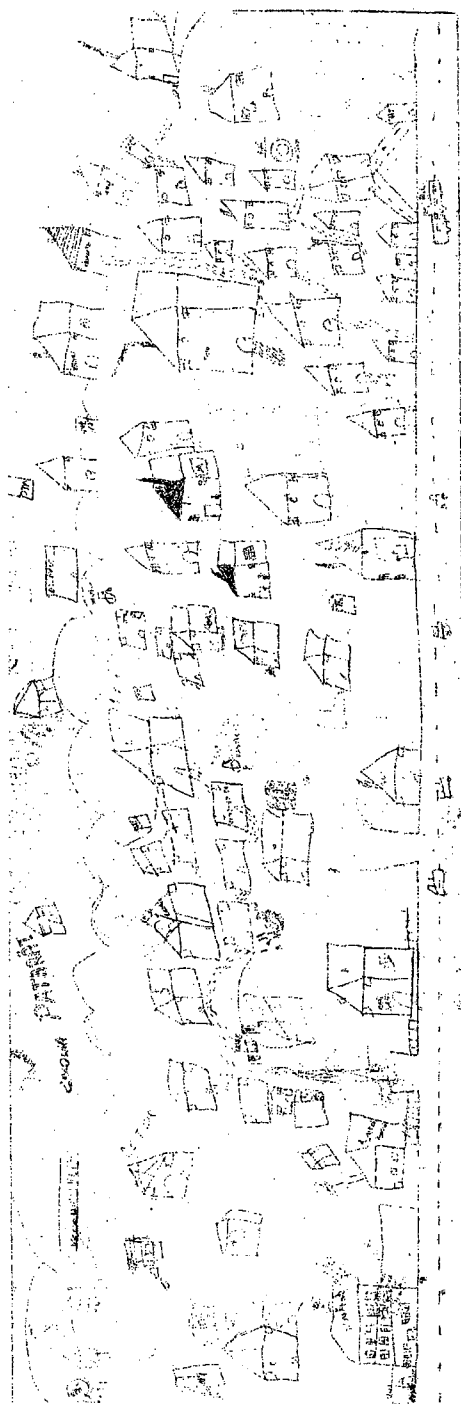


Figure 9. Scanned image of community map made by YVM/FAF Roma youth group

Along Pata Rat Road

Before we take a walk and I show you around Dallas, I would like to sit for a moment at the YVM/FAF New Life Education Center. I have a headache, so if you do not mind we will hang out here for a little while before we go. I get headaches almost every time I come out here, but they usually go away or at least get to a point where I do not notice them anymore. In the meantime, I will set us up a couple of chairs here at the entrance, just as I have done with many of the locals on a number of occasions. We can watch daily life and movement along Pata Rat road while we wait.

Smells of burning metal, plastics, and toxic chemicals permeate the air. They even make my eyes squint and forehead pinch together. These smells are actually quite common around here because the local waste pickers burn the outside of electrical wiring to get the metal/copper to recycle. During this incineration process, the wiring releases dioxins, furans, hydrogen chloride, and phosgene into the air. In addition, the outside of the wiring is often made of plastic or rubber and creates intense smells and thick black smoke. Generally, the burning takes place on the perimeters of the community like you can see over there on the hill in Figure 10.



Figure 10. View of open burning from YVM/FAF New Life Education Center image 1

Right now, it is about 2:15 in the afternoon and there are four people burning; however, this activity takes place throughout all hours of the day. It is difficult to describe the smell, but it is overwhelming and making me feel nauseous. The other day people were burning in an area that appeared to be about 10 feet from one of the water sources, if not closer. It caught my eye how normal it seemed as women and children used water at the same time. A woman washed her large, brightly colored rugs while another woman approached and collected water in an uncovered red bucket. A few children followed, washed themselves off, and drank directly from the spout; all the while smoke filled the air.



Figure 11. View of open burning from YVM/FAF New Life Education Center image 2

Many times those who are tending the fires get lost in the smoke, like those pictured in Figure 11, before the wind carries the clouds of smoke up and across the community. As a result of this recycling process, the Roma have a high risk of exposure to multiple pollutants in smoke. The chemicals and pollutants listed in Table 4 (Bruce, Perez-Padilla, & Albalak, 2000, p. 1085) can have a wide-ranging impact on their health and well-

being. These include in addition to respiratory effects, effects on immunity, cancers, the endocrine system, and also potential birth defects, teratogenic impacts, and learning disabilities.

Not only do the Roma burn electrical wiring for recycling purposes, but they also burn items for cooking, heating their homes, making warm water for baths, and melting ice in the winter. These burning activities are basic survival skills the Roma have adopted as a result of poverty and poor environmental conditions. Some of the common items they burn for such activities when wood materials are not available are shoes, tires, clothing, and plastics. Colored plastics are especially harmful because their pigments contain highly toxic metals including copper, lead, chromium, cobalt, selenium, and cadmium (Edugreen, n.d., p. 2). Moreover, when wood is available, it has often been treated, thus resulting in increased exposure to toxic chemicals. For example pressure treated wood contains arsenic, chromium, copper, creosote, chlorophenol (PCP), diesel fuel, and pentachlorophenol. Plywood, particleboard, or paneling contains arsenic and formaldehyde; and lastly wood that has been painted or varnished contains benzene, dioxins, and lead.

Table 4

Key pollutants in smoke that may increase risk of respiratory and other health problems

Pollutant	Mechanism	Potential health effects
Particules (small particles less than 10 microns, and particularly less than 2.5 microns aerodynamic diameter)	Acute: bronchial irritation, inflammation and increased reactivity; Reduced mucocilliary clearance; Reduced macrophage response and (?) reduced local immunity; (?) Fibrotic reaction	Wheezing, exacerbation of asthma; Respiratory infections; Chronic bronchitis and chronic pulmonary disease; Exacerbation of chronic obstructive pulmonary disease
Carbon monoxide	Binding with haemoglobin to produce carboxy haemoglobin, which reduces oxygen delivery to key organs and the developing fetus.	Low birth weight (fetal carboxy-haemoglobin 2-10% or higher); Increase in perinatal deaths
Polycyclic aromatic hydrocarbons, e.g. benzo[a]pyrene	Carcinogenic	Lung cancer; cancer of mouth, nasopharynx and larynx
Nitrogen dioxide	Acute exposure increases bronchial reactivity; Longer term exposure increases susceptibility to bacterial and viral lung infections	Wheezing and exacerbation of asthma; Respiratory infections; Reduced lung function in children
Sulphur dioxide	Acute exposure increases bronchial reactivity; Longer term: difficult to dissociate from effects of particles	Wheezing and exacerbation of asthma; Exacerbation of chronic obstructive pulmonary disease, cardiovascular disease
Biomass smoke condensates including polycyclic aromatics and metal ions	Absorption of toxins into lens, leading to oxidative changes	Cataract

Table 5 (adapted from Agency for Toxic Substances and Disease Registry, 2008; South Dakota Department of Environment and Natural Resources, 2005) points out several chemicals that are released from burning a variety of solid waste materials.

Table 5

Chemicals released when burning solid waste

Items Burned	Chemicals Released
Tires	styrene, butadiene, benzene, lead, chromium, cadmium, hydrogen sulfide, mercury, zinc
Shoes	hexane, styrene
Electrical wiring	dioxins, furans, hydrogen chloride, phosgene
Pressure treated wood	arsenic, chromium, copper, creosote, chlorophenol (PCP), diesel fuel, pentachlorophenol,
Plywood/wood, particle board, paneling	arsenic, formaldehyde
Plastic items, PVC piping, furniture, toys	acrolein, benzene, cadmium, carbon, tetrachloride, chromium oxide, dioxins, furans, hydrogen chloride, hydrogen cyanide, lead, phosgene, styrene
Nylon clothing	nitrogen oxide
Cotton clothing	acrolein, formaldehyde
Wool clothing	hydrogen sulfide
Paints, varnishes, cleaning supplies	benzene, dioxins, lead, methylene chloride, methyl ethyl ketone, perchloroethylene
Foam cups, egg cartons, yogurt containers, plastic forks and spoons, etc.	benzene, chlorinated furans, dioxins, styrene
Magazines, slick covered paper and cardboards	lead, cadmium

As we sit here enjoying the sounds of the birds chirping and the wind blowing through our hair, a Roma man with his horse and wagon go by (as shown in Figure 12). The horse's trot offers a steady rhythm that together with its bells, provides a rather musical experience, at least when the garbage trucks and other traffic are not drowning them out.

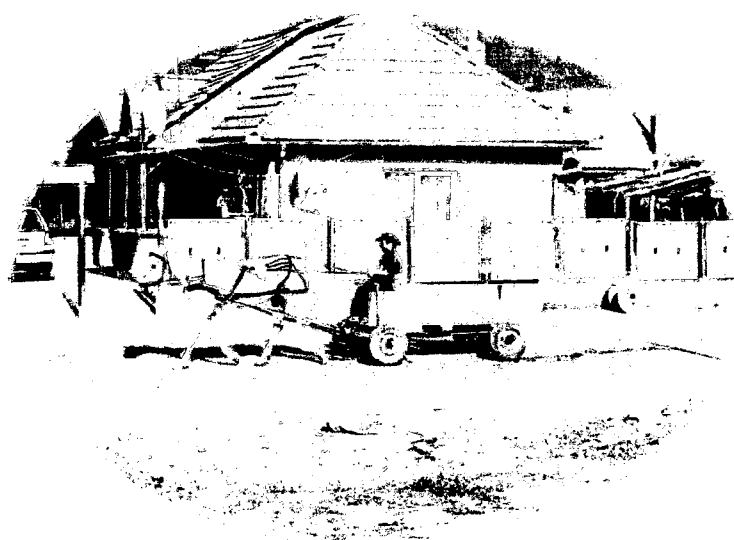


Figure 12. Horse and wagon along Pata Rat Road

The horses carry their Roma masters and wagons, which are sometimes empty and other times overflowing with people, recyclables, and/or reusable treasures. The horses vary in multiple shades of brown, black, gray, and white. A dark chocolate horse passes by now with a man and a woman holding her baby. Their wagon is empty and looks like they are heading to Rampa to work. A light brown horse follows with a couple adolescent boys, then a beautiful dark gray horse with red, floppy frills hanging by each ear. His master is

wearing a big brown hat and whips him to speed up as they pass by. A woman and her two young children are sitting in the back of the empty wagon. Next, a white horse whose male master wears a light blue top hat goes by with his wife and adolescent girl. They share the wood built wagon with a fridge and metal sink. The relaxing rhythm of the horses soon fades as a Brantner Veres garbage truck, the leading waste collection business in the area, approaches and quickly passes by. The truck, as shown in Figure 13, is part of a steady flow of traffic.



Figure 13. Brantner Veres garbage truck going towards Rampa

The smell of diesel fuel and leaded gasoline fill the air as the dump trucks, tractors, and other vehicles go by. As they pass, dust and debris fly up, form clouds, and float across the rooftops of Dallas. That is in addition to the thick, black exhaust and fumes from transit, including tractors, cars, garbage trucks, and other large vehicles. The exhaust contains particulate matter, which affects the respiratory and cardiovascular

systems. Signs and symptoms from high exposures to particulate matter include bronchitis, pneumonia, asthma, wheezing, chronic cough, decreased lung function, and cardiovascular conditions (Dunn, Burns, & Sattler, 2003). After the vehicles have passed, the smell of gasoline and diesel that so quickly permeated the air, gradually returns to the smell of burning plastics and metals.

Several people are going by on foot now, including the woman pictured in Figure 14. She is an individual scavenger and on her way to Cantonului. Three adolescents pushing a stroller filled with metals and what looks like iron bed springs follow along with a mother and child carrying a large loaf of bread and a 2-liter of orange pop.



Figure 14. Individual waste picker/scavenger walking towards Cantonului

As the horses, wagons, and garbage trucks continue to go by a small white car from across the street pulls out (see Figure 15). It is transporting an overflowing load of white plastic bags filled with plastic recyclables to a nearby collection center. The car is driven by one of the locals who manages a local waste cooperative (co-op) in Dallas.

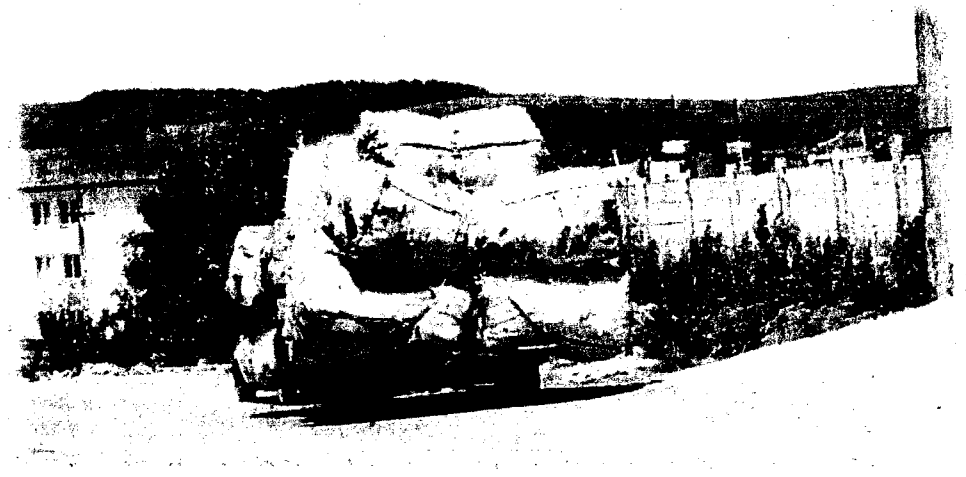


Figure 15. Car taking packaged plastics to collection center

There are two major co-ops, like the one in Figure 16, located in Dallas. They provide a place for individuals and families to weigh and sell their recyclables. The co-ops accumulate recyclables into commercially viable amounts then sell them to the larger recycling collection centers. Some family units also have their own scales and do not utilize the co-op services. There are two main collection centers: a blue one down the street towards Rampa, which was built in between May 2008 and May 2009; and one located about 2-3 km the other way towards where the white car was heading earlier.

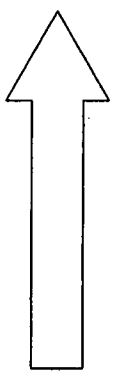


Figure 16. Recycling cooperative in Dallas

In Dallas, there are “four hands.” In other words, there are four levels in the hierarchical system of the informal recycling sector among Roma community members. They are individual scavengers, family-type units, scavenging co-operatives, and middlemen. This hierarchical system, illustrated in Table 6, is characteristic of the informal recycling management system (Wilson, Velis, & Cheeseman, 2006, p. 800). Although scavenging provides a number of economic benefits, the way in which the informal sector is organized has important implications for working conditions, income generation, and social status. Generally, the higher one is on the hierarchy the more money one makes and thus the more respect and higher status one has (Wilson et al., 2006).

Table 6

Hierarchy in the informal recycling sector

	Highest Value	Manufacturing industries
		Brokers, wholesalers, and other Processors
		Craftsmen, middlemen
		Recycling MSEs and scavenger co-operatives
		Family type units involved in waste collection or scavenging/picking
	Lowest Value	Individual waste scavengers/pickers

In “Pata Rat,” individual scavengers are at the bottom of the hierarchy and the most vulnerable. Remember the woman who walked by earlier in Figure 14? She was an individual scavenger. Family and organized groups are higher on the hierarchy because they share a level of social and economic support that the individuals do not have. Co-operatives and micro or small enterprises (MSEs) like the one pictured in Figure 15 are higher yet and are among the wealthiest members in the community. They provide primary collection and processing for collected materials and respond to market needs (Wilson et al., 2006). Finally, there are a few middlemen in “Pata Rat” who sell recyclables to other brokers or processors. The items are often larger items like old appliances or electronics.

“In the context of municipal solid waste management (MSWM), the informal recycling sector refers to the waste recycling activities of scavengers and waste pickers” (Wilson et al., 2006, p. 797). The Roma make up a significant part of the informal recycling sector in Romania and Women for Informal Employment and Organizing (n.d.) point out multiple economic benefits that scavengers provide. Informal recycling:

- Contributes to public health and sanitation: (especially street collectors)
- Provides employment and source of income.
- Contributes to environmental sustainability.
- Reduces municipal expenses.
- Reduces the need for expensive exports. (n. p.)

It is about 3:20 p.m. now and a school van has stopped at the green house across the street. A few children get out while the majority of the other children, who do not attend school, can be seen playing in and around Dallas. Several are playing on the hill in the black dirt areas where they burn the wiring. There are only a few children that attend school, but I am not sure exactly how many. One day when I was visiting with a husband and wife at their home, their son came home from school with his backpack. They live in a concrete home, own a car and even have a blue, inflatable swimming pool.

On the other hand, I discovered there is still a deep feeling of distrust toward the school system by many of the Roma. Not that long ago a boy from Dallas went to school and was beaten with a chair by his teacher. He was hit across the face so badly he had to go to the hospital. He returned to the community full of stitches and bandages; hence, he did not return to school again and the distrust for the non-Roma school system was

deepened in the community. Another feeling is that for the children who do go to school, they do not seem to be learning very much. Teachers tend to pass them to higher grade levels even if they cannot read and are not improving. They do not seem to care to provide the extra assistance they need, so basically the children just sit in class (C. Aschilean, personal communication, May, 2009). Yet another barrier is transportation. There is a small van that picks children up and drops them off like we just saw; however, that is only for a few. There used to be a school bus that came to "Pata Rat," but in 2008 they changed the route and the bus no longer comes to pick them up. As a result, many children who were going no longer go. (C. Aschilean, personal communication, February 2009). There was, and maybe still is, a government incentive program that would pay a small amount each month to encourage children to go to school. The amount was very small and could be made in one day of recycling; therefore, there was not much benefit, at least monetary, for parents to send their children to school (C. Aschilean, personal communication, May 2009).

The other way to get to school, or even into town, would be to take the public bus system, which is about a 20-30 minute walk and is an unsafe route for children. I know because I walked it myself, and I took the bus into town, actually two buses, because there is not only one bus that would take me to where I needed to go. I walked towards Cantonlui down along the side of Pata Rat Road where there was a lot of traffic and large garbage trucks, several of which seemed to be going a lot faster than the designated speed limit. At the end of the road, before you would turn to go towards Cluj, there is a short, steep hill with lots of rocks. I went up the hill and then crossed railroad tracks. After

crossing the tracks there is what seems, the steeper side of the hill, steep enough that I pretty much ran down it so I would not fall. At the bottom I passed through a small trail among bushes and trees before coming out on a short paved street. From there and straight a couple of blocks there is a major city road. On the other side of the road and down a few minutes, is the bus stop. Additional barriers to going to school for the Roma of Dallas are poor health, poor hygiene, lack of clothing, lack of school supplies, and lack of appropriate documentation.

My headache has pretty much gone away and the fires are subsiding (Figure 17), so this is a good time to take our journey through Dallas. Before we do, I recommend that you change your shoes. At times we will be walking through debris, stagnant water, and soil that are likely to be contaminated. Moreover, the blackness from the soil is almost impossible to get off your skin, at least with standard soap. I unfortunately found that out the hard way the day we did the community mapping. I wore sandals and my feet and toes were literally as black as chimney soot. That night I scrubbed my feet harder and longer than I ever have and I still could not get all the black dirt off, especially around my toes. The soil was embedded in my skin, so you can only imagine what it is like after daily and prolonged contact. I will put the chairs away while you get ready.



Figure 17. Boy tending fire

Community Walk Through

We are now entering Dallas where I almost always enter, that is right between the two houses across from where we were sitting at the YVM/FAF Center. The house on the left was just built within the last year and is one of the newer recycling cooperatives. We are taking one of the three main paths, as shown in Figure 18, and is actually the first of the three intersections community members identified on the rock map.



Figure 18. First intersection of Dallas

Up here to the right, just behind where are the people are, there used to be a water well, but it is no longer functioning. “It has been estimated that in many poorer communities between 35 and 50 percent of water and sanitation systems break down and become useless after five years” (Lankester, 2007, p. 318). Dallas used to have five wells, but in the last few years this number has reduced to three, including going from four to three sometime after May 2008. It is highly probable that this number will continue to decrease in the near future by the wells’ current condition and lack of monitoring. You will see what I am talking about when we get to the first functioning water source at end of this path.

Up here to the left of us is where many community members live. Many of the homes to the left are made from wood, are mostly comprised of one room, and have been built over the last few years. There are also quite of few shacks in the area. Straight ahead is the first water source (Figure 19). A mother and her two children are doing their laundry as a horse stops by for a quick drink. In the back of the wagon, it looks like they

have found a new door or possible wood to use for burning. As you can see, a variety of activities in addition to collecting water, take place at the well.



Figure 19. Washing laundry with horse at water well

Additional activities include, and are not limited to, washing dishes, washing food/meat like the child washing raw sausages in Figure 20, drinking water directly from the spout, and finally cleaning themselves off like the children in Figure 21.



Figure 20. Girl washing raw sausage at water well



Figure 21. Children washing themselves off at water well

This well we are looking at is the most frequently used water source in the community. It clearly has an extremely high risk of contamination and not only from improper use. It

also has very high risk of contamination from solid waste reaching the ground water.

Here, come closer and take a look inside and be careful not to slip. It is very slimy and slippery around here (Figures 22 and 23).



Figure 22. Inside first functioning water well image 1



Figure 23. Inside first functioning water well image 2

As you can see in Figures 21 and 22 the well is full of solid waste, including different types of plastic, some sort of sign, aluminum cans, and even a hat. The debris

you are seeing inside this well is a similar in comparison to debris found in the two other wells, which we will visit later. A woman is arriving now to collect water in a red, plastic, uncovered bucket. So, we will go up this hill so we are not in her way and I will show you more of Dallas. Before we go too far, turn around and look back at the well (Figure 24). From here, you can see the stagnant water (red arrow on the right) that accumulates below the well in addition to a large amount of waste located slightly uphill and very near to the well (green arrow on the left).



Figure 24. View of Dallas from behind functioning water well 1

The area of homes you are seeing straight ahead is the area behind the bar/restaurant. That was the area to our left that I showed you earlier when we were walking along the first path. As we continue our way up the hill, watch your step along the way. There are feces scattered everywhere along here, including human, dog, and horse feces. This is actually one of the areas where many people come to defecate. Many people also defecate beside their homes. We will stop here so I can point a few things out to you (see

Figure 25). Looking at the top right corner of the picture to the right of the red arrow you can see the bar/restaurant, which is the large three-story building. The green and yellow buildings (see red arrow) across Pata Rat Road from the bar/restaurant (see blue arrow), where you can just see the rooftops are the YVM/FAF New Life Education Center, Health Clinic, and Public Shower/Restroom. That is actually where we were sitting earlier when we were watching people burning recyclables on the hill close to where we are now. This is also a spot that many of the youth in the photovoice activity stopped and took pictures from. They all really liked this view and looking out and seeing the whole community.



Figure 25. View of Dallas from hill image 1

Looking a little more to the left, as seen in Figure 26, you can see more of Dallas. Notice how the built environment is quite developed in that area. It shows you how Dallas is not just a settlement with shacks made out of debris, which is what the Roma want you to see. The Roma have built their homes and their lives here. The sad thing is there is a possibility they may lose it and have to start over again.



Figure 26. View of Dallas from hill image 2

In the middle of the image you can see five rather newly structured homes (see red arrow), their roofs all nicely lined in a row; that is the second or middle intersection that was illustrated on the rock map. The blue fenced area in the top of the image is the collection center (see blue arrow). There are two cement houses across the street including one with a green roof and a larger house with a purple roof. To the right of the larger house is the 3rd of the intersections. It is not quite as clearly defined as the other two. On both the 2nd and 3rd intersections there are local markets where staples like oil, butter, pasta, and bread are sold. Before we go to the next water source, I want to show you the kindergarten. We will go down this hill right here. Be careful. It is kind of steep.



Figure 27. Kindergarten and school latrine in Dallas

The kindergarten is the built wood building in the back in Figure 27. They offer early childhood education programs three mornings a week. The wood latrine in the front is used by the children during kindergarten hours, otherwise it is locked. It is definitely the most properly maintained latrine in the community. There is a small shack home in between the kindergarten and the latrine where seven people live. The father has a job in Cluj and you can often see the mother cooking for her family and offering her leftovers to neighbors. She feels lucky that her husband has a job and therefore her family is able to eat well, unlike others in the community who are often lucky to cook one meal a day.

From here, we will visit the next functioning water well. It is located back up the hill a bit and if we turn around we can see it from here (Figure 28). This well (see green arrow) has a concrete base, unlike the first well, but the same as the third and final one. The white door on the left top corner of the image (see blue arrow) is the entrance to a latrine, which is improperly managed like many of the latrines in the community. In my

earlier count of latrines in the community, I counted 22; however, I did not check to see if they were all in use. Of the latrines that I entered all were poorly managed, turned into storage, or completely broken, thus the number 22 is likely to be an overestimate of the number of latrines, at least that are operable. Feces and urine can pollute water, food, and soil with microbes and worms and lead to serious health problems (Conant & Fadem, 2008).

When you get close to the latrine the smell is absolutely horrifying/sickening. The natural reaction is to hold your breath until you cannot hold it anymore. The trick is to pretend it does not smell bad and pretend you are not holding your breath. I had to do this, especially when I was taking photos. Additionally, insects and flies were everywhere. These flies that come in contact with fecal matter spread bacterial infections and cause illness (Cointreau, 2006). I never saw very much toilet paper, actually only once, but maybe they keep it in their home. You could tell some people use paper like notebook or newspaper to wipe, while it appears others do not use anything. A couple of the latrines were also layered with old clothing, I imagine for covering up the smells but also maybe for wiping. Lack of proper wiping, especially in girls, can spread germs into the urinary opening and cause bladder infections and other health problems (Conant & Fadem, 2008). We will not go any closer to the latrine as I think you can understand my point without me showing you.

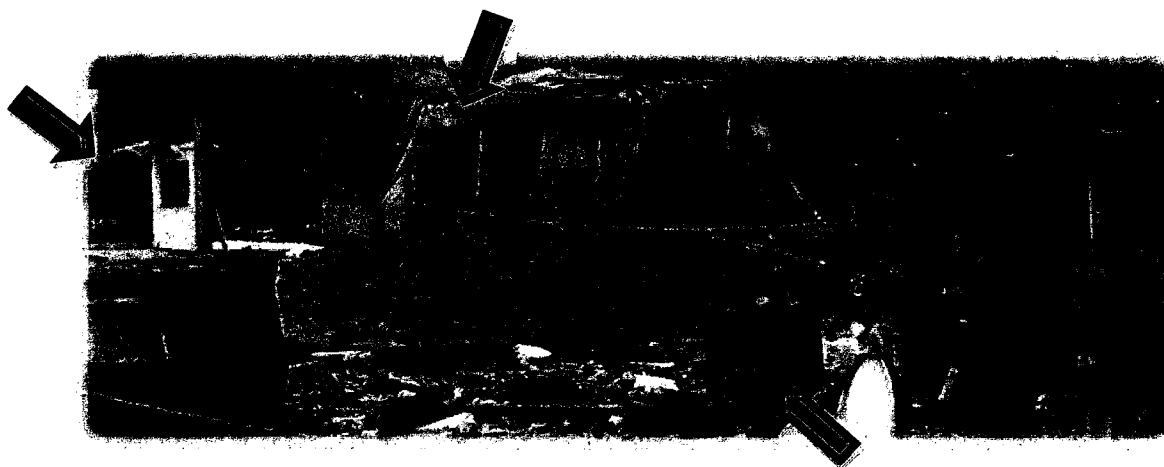


Figure 28. Functioning water well with latrine and animal dwelling

Again, looking at Figure 28, you will notice an animal living quarters/horse dwelling within 20 meters. You can see there is actually a horse going in there right now (see red arrow). Both the latrine and the horse's dwelling are located uphill making the well water much more susceptible to contamination. Solid waste surrounds the area around the well, also indicating probable contamination. Furthermore, both the black dirt areas on the top right and left of the well (not pictured) are open burning sites. These areas of black soil are likely to be contaminated with multiple toxic chemicals including arsenic, cadmium, chromium, and creosote that can easily penetrate groundwater. All of the above combined; the proximity of the latrine, the proximity of the horse dwelling, the solid waste piles, and the open burning sites creates multiple pathways of possible water contamination, which all lead to illnesses. On top of all this, the well is visually broken with water spurting out from breaks in the piping (Figure 29) and like the first well, it is filled with solid waste.



Figure 29. Inside second functioning water well

Diarrheal diseases are the most frequently encountered consequence of contaminated water supplies and despite improvements, are still one of the leading causes of death for children under age five (Cointreau, 2006). Most diarrhea diseases including cholera, typhoid, giardia, bacterial dysentery (*Shigella*), amebic dysentery, roundworm, hookworm, and whipworm are caused by toilets that are not clean and safe, lack of water for personal cleanliness, and contaminated water and food (Conant & Fadem, 2008). Diarrhea is very common in Dallas, especially during the summer (Dr. Florescu, personal communication, May 2009). Moreover, throughout my time in Dallas, I saw many women and children holding their stomachs from sharp pains and also visually saw diarrhea alongside houses and in latrines.

The community of Dallas does not have the luxury of waste or sanitation services, so local waste accumulates throughout the community, and as you have seen, even in the water wells. On the bottom right of Figure 30, you can see a small pile of waste with used

drums lying on their sides that may have previously contained toxic chemicals or waste. A stove (see red arrow) and tables with pots, pans, and dishes are located behind the drums illustrating the proximity of solid waste to food handling and preparation.



Figure 30. Solid waste pile with empty drums behind home in Dallas

The family's home (see green arrow) is located just behind the waste pile making it likely that rats and other vectors enter the home. Rats are commonly seen in and around solid waste piles in Dallas and can even be seen during the day. The other day at the last well we were at, a large rat scurried out of the nearby waste pile. Three children ran after it, but within seconds were stopped by their mother who yelled at them to stop chasing it. Some families keep their lights on at night to try and keep the rats out while other families with concrete homes worry about the rats and their fellow community members. Possible diseases that are directly transmitted by rodents that have been in contact with solid waste include Hanta Virus, Leptospirosis, Lymphocytic Chloriomeningitis (LCM), Rat-Bite fever, and Salmonellosis. Table 7 (adapted from Centers for

Disease Control and Prevention, 2006) shows how each disease spreads. For example, in addition to rat bites, diseases are spread by breathing in dust, eating food, or drinking water that has been contaminated with rodent or urine droppings.

Table 7

Diseases directly transmitted by rodents

Disease	Agent	Rodent Involved	How Disease Spreads
Hemorrhagic fever with renal syndrome	Virus	Striped field mouse; the brown or Norway rat; the bank vole; and the yellow-necked field mouse	Breathing in dust that is contaminated with rodent urine or droppings; Direct contact with rodents or their urine and droppings; Bite wounds, although this does not happen frequently; This disease may spread through direct contact from person to person but it is extremely rare.
Leptospirosis	Bacteria	Rodents and other animals	Eating food or drinking water contaminated with urine from infected animals; Contact through the skin or mucous membranes (such as inside the nose) with water or soil that is contaminated with the urine from infected animals.
Lymphocytic Choriomeningitis (LCM)	Virus	House mouse (<i>Mus musculus</i>)	Breathing in dust that is contaminated with rodent urine or droppings; Direct contact with rodents or their urine and droppings; Bite wounds, although this does not happen frequently.
Rat-Bite Fever	Bacteria	Rats and possibly mice	Bite or scratch wound from an infected rodent, or contact with a dead rodent; Eating or drinking food or water that is contaminated with rat feces.
Salmonellosis	Bacteria	Rats and mice	Eating or drinking food that is contaminated by rat feces.

Figure 31 provides a close up image of a waste pile in Dallas. This gives you a better idea of what community members are living among, but it is not representative of the wide variety of waste that can be found in Dallas.



Figure 31. Close-up view of waste pile in Dallas

Nevertheless, the numerous waste piles throughout the community do not prevent the Roma from doing their daily activities, like hanging and drying their laundry (Figure 32). You can see they literally walk over the trash like we would walk on green grass. On several occasions, I have had to walk over or through the trash, especially when I was following community members. At times, I walked over soiled rugs, plastic bottles, old clothes, and even an old metal box spring from a mattress. For our journey we will stick to the paths.



Figure 32. Laundry hung over waste pile in Dallas

Children also enjoy playing in and around the debris and since the majority do not attend school, the number of hours spent playing with the waste is very high, thus exposing them to high levels of toxic chemicals. In a study in Copsa Mica, Romania, blood lead levels of children (4-6) were tested and concluded that the primary sources of lead in the blood are soil and household dust, not air. This is in part because lead particles in the air become dust and later settle into the soil. Lead concentration levels were positively correlated with certain behaviors including the time children spent playing outdoors (Surdu, Neamtii, Gurzau, Kasler, & Carpenter, 2006). Because parents and older siblings are often working, many children in Dallas are often unsupervised, thus spending long hours playing among waste and contaminated soil. They are hard to see among the waste, but four children (Figure 33), enjoy playing in and around piles of debris with one child on the ground (see green arrow). While the children are playing, a

man is seen in the top right of the image (see blue arrow) loading recyclables in a large white truck from one of the homes.



Figure 33. Children playing in waste piles in Dallas

Not only do the children likely pick up lead poisoning and other chemical exposures by playing in solid waste piles and contaminated soil outside their homes, but they are also exposed to contaminants inside their homes. With lack of proper hygiene and sanitation and occupational health and safety services, parents and family members bring toxic chemicals into their homes through their unwashed clothes and skin after working with hazardous waste in Rampa. For example, lead, arsenic, cadmium, and dioxins are all found in municipal waste and stay on skin, clothes, and hair (Agency for Toxic Substance and Disease Registry, 2008). Figure 34 illustrates how the toxic dirt stains the scavenger's skin and passes onto the outside of their home.

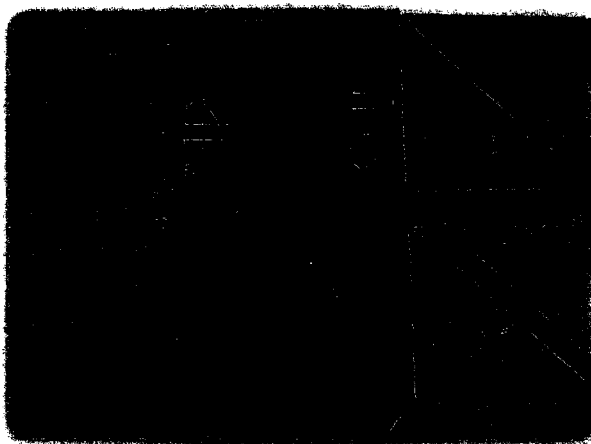


Figure 34. Saturated skin, clothes, and home with contaminated soil after working at Rampa

Looking inside a home (Figure 35), you can see how the toxic soil even covers the bedding. The child's stained hand is holding an empty bottle, which most likely previously contained contaminated water. Worse yet, the toxicant is all over his face, caked in his ears (not pictured), and blocking his nasal passage.

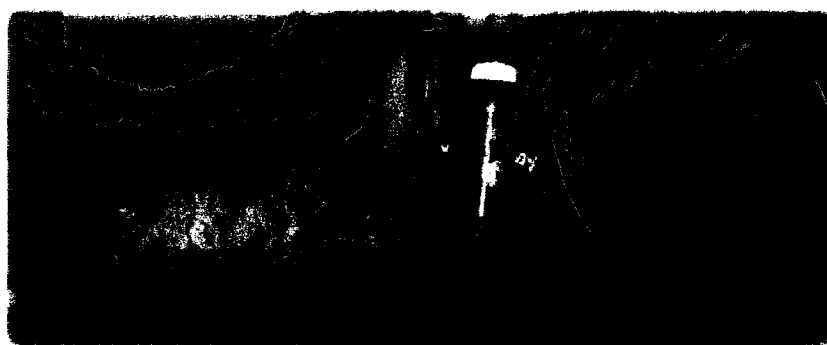


Figure 35. Child on bed in soil contaminated home

This means the poor child is breathing in chemicals with each breath. Some homes are worse than this while other homes are better. It really depends on the hygiene and sanitation habits of the parents and also where one stands on the hierarchy in the informal recycling sector.

The mother of the 2-3 year old child pictured in Figure 35 is working at Rampa and his brothers and sisters do not know how to take care of him, let alone take care of themselves. They, too, are covered from head to toe with the toxic soil. The other day I taught a bunch of children how to play thumb war, a game where two people interlock their hands and try to push the other's person thumb down with their thumb. When I was playing with the different kids, primarily the brothers and sisters of the above child, their hands were filthy with dirt caked under their fingernails.

From here, we will now visit the last of the community's functioning water wells. We will walk around the side of the community over here on this path, which is frequently used by horses, wagons, and people. It is better than walking through the waste, stagnant water, and contaminated soil. Straight ahead and to the left is one of the two pig dwellings. Three of the five pigs in Dallas live there. The other pig dwelling is located in the community. The pigs are later butchered and the meat is consumed, which likely contains a bioaccumulation of toxins. The extra meat is sold to fellow community members.



Figure 36. View of Dallas with third functioning water well

We will stop here for a moment (Figure 36). This is a good view of the last well and of Dallas. A couple years ago, in May 2007, there were more homes located in this area. I know one family built a new cement home and another one burned down. I imagine accumulation of stagnant water, which by the way is a breeding ground for disease (Edugreen, n.d.), may have also motivated people to move away. As you can see, the area surrounding the well accumulates a large amount of stagnant water. This is because of its location on flat ground and lack of drainage. The well (see green arrow), like the second one, has a cement base, and similar to all wells, is not covered. The large, blackened soil area to the right is where the house used to be that burned down (see red arrow). It burned down last year and the man that lived there actually died (Youth Photovoice participant, personal communication, May 2009). Straight ahead from the well and a little to the left is one of the blue rented port-a-potties. It is one of two rented ‘latrines’ in the community. These were new to the community sometime between May

2007 and May 2008. In the top far right, you can see the second main recycling co-operative (see yellow arrow), and towards the top-left (see blue arrow), you can see the top part of the bar/restaurant. Seeing the bar should now give you an idea how we have walked around the community. Before we head over to Rampa, I want you to take a closer look at this last well and the stagnant water (Figure 37). The spout is broken and they wrapped it (see red arrow) to prevent leaking; however, when the spout is turned on, water sprays out from the cracks.

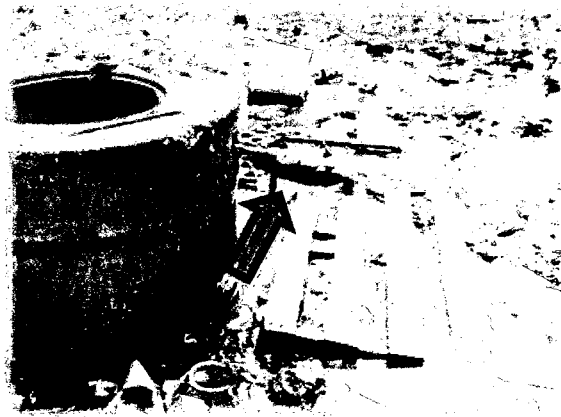


Figure 37. Stagnant water around third functioning water well

Just like the previous two wells, this one is also filled with solid waste (Figure 38). You can see in this well, there is wiring and plastics including an item that I believe has something to do with batteries.



Figure 38. Inside third functioning water well

During the household interviews, we asked respondents to name two current community health problems. They identified the following as problems found in Dallas: lack of cleanliness, garbage, dust, the water, the dirt and dirty things, the smells from burning items, mushrooms/fungi, rats, latrines and their proximity to houses, their work on Rampa, and finally, misery, which was the most frequent answer. Almost one third of respondents (0.3225) or 10 of the 31 households answered “misery” to the open question about Dallas’ current community health problems. Their responses illustrate that community members are aware of and are able to point out many environmental health problems that are making them ill. Although the Roma did not specifically say chemical or toxic exposures, they demonstrated knowledge of the route of exposure (air, dust, dirt, water, solid waste, and rats). A concern I have is that even though many community members are able to perceive chemical contamination, they have little control over the toxins in their environment. Unlike tobacco smoke, which you can choose to limit your exposure to, the Roma have little to no choice in their exposures to toxic chemicals,

primarily because they do not even know the chemical is there. One of the most important reasons exposures to environmental toxicants is problematic:

is that low doses of toxicants are completely invisible, often completely unsmellable (i.e., they often occur in concentrations well below the olfactory threshold), and thus are virtually undetectable by all normal human abilities to perceive. There is thus no simple way to determine when and whether one is being exposed to these chemicals (Kerns, 2001, p. 11-12).

Through our observation at the YVM/FAF Center and our journey through Dallas, you can see the community faces a number of environmental health conditions that are cause for great concern including: open dumping and uncontrolled solid waste piles; air, water, and soil contamination; and chemical exposures. Before we discuss more about how these conditions are affecting the Roma's health and well-being we will visit Rampa. Because their occupation is so closely connected to their environmental living conditions, their health status could not adequately be predicted without discussing their occupational health risks. The walk is about 1-2 kilometers down Pata Rat Road. While we walk to Rampa, I want to share a few things community members told me that they wanted to change about Dallas. My purpose is to share these requests with you for them, since the opportunity for you to hear this directly from them is not likely to happen without this advocacy effort.

First, regarding their stay, some Roma in Dallas would like to be allowed to stay here if and/or when Rampa closes, while others are looking to move to another village, county, or even country. For the time being, however, and for those who want to stay, they would like to have garbage pick-up with trash containers and an underground sewage system like they have in the city. They also want concrete streets and home

addresses so they can get mail and identity cards, which several need. The exact number is unknown and a follow-up study is recommended to find out. Some Roma want to move from their shacks into wood-built or concrete-based homes, while others want to have water available in their home and own property. Many Roma would like to see their community clean, with improved hygiene and latrines, including a public restroom in the community. Finally, many Roma do not want to “have” to work at Rampa. What is important to highlight about the Roma’s desires are that they not only represent changes they would like to see in their community environment, which would drastically improve their environmental health, but more importantly their desires are about having their basic human and community rights met. I will further address the Roma’s desired changes and my recommendations for these changes in the next chapter. Right now we are arriving at Rampa.

Rampa



Figure 39. Entrance to Rampa, Cluj-Napoca's municipal landfill

We are now entering Rampa, Cluj-Napoca's Municipal Landfill (Figure 39), where over half of the adult community members of Dallas work along with adolescents and even some younger youth. Scavengers are also from Cantonului and here in Rampa. Scavenging provides employment and a livelihood for the people of Dallas and "Pata Rat" and they work very hard doing it, sometimes going the whole day without food and/or water.

The scavengers of "Pata Rat" have a somewhat organized system. First, they follow the garbage trucks to their site of disposal as seen in Figure 40. This is done so they can get first access to the freshly disposed waste. Their proximity to the dump trucks means they are regularly in close contact with gas and diesel fumes and exhaust, thus exposing them to high levels of particulate matter. Breathing very high levels of automotive gasoline and polluted dust, which contains benzene and lead, can result in

drowsiness, dizziness, headache, rapid heart rate, tremors, confusion, unconsciousness, and even death (ATSDR, 2008).



Figure 40. Roma scavengers following garbage truck to disposal site

After the waste is dumped, the Roma pick through the piles for recyclables, even before the garbage truck has left, as pictured in Figure 41. They each have a bag and many use a long stick to poke through the piles. You can see they are all working hard to get the most recyclables they can, like the man by the truck (see red arrow) with plastic bottles in both hands. The Roma primarily collect plastics and ferrous metals, including aluminum and copper. Additional and larger items like old appliances are collected and sold through middlemen. Many times, these appliances are collected by the Roma waste pickers that scavenge in Cluj. It is not uncommon to see the Roma in their horse drawn wagons in neighborhoods around Cluj. Many times when I walked to the YVM/FAF's office and church in Cluj-Napoca, I would see the Roma scavenging along the way. In the past, glass and cardboard were also collected, but to my understanding they are no

longer being purchased; therefore, they concentrate on what recyclables they can get the most profit from.

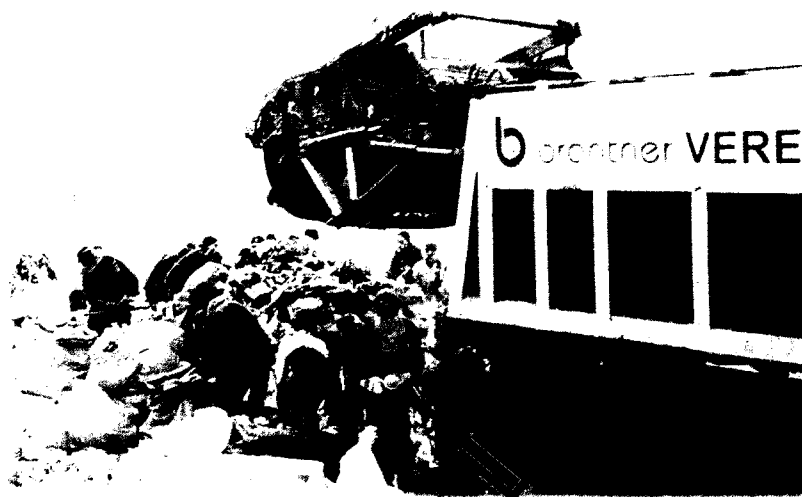


Figure 41. Scavenging in Rampa at point of disposal

Being so close to the operating trucks puts the Roma in increased risk of accidents, injuries, disability, and even death such as being hit or even run over. Injuries cause nearly 6 million deaths each year worldwide, and the number is rising. Furthermore, death and disability from injury occur disproportionately among children and the poor. Injuries, as an environmental health issue, have been neglected and little is done to prevent them in developing countries. “Part of the problem is that injuries, particularly non-fatal ones, often go unreported” (Cairncross, O’Neill, McCoy, & Sethi, 2003, p. 4). Injuries were observed among the people of “Pata Rat” in their limping, movement from physical pain, and open cuts and burns on their arms, legs, and feet.

Since, there are no sanitation services at Rampa and no water source for hydration, some actually resort to consuming items from the waste they are picking, like the young teenager (see red arrow) in Figure 42. This also means there is no area to go to the bathroom or wash themselves off before returning home. Furthermore, if an accident or chemical burn would occur or someone would need an eye flush or emergency care, there are no first aid services available. Wounds are also a concern for the Roma people because they provide an open pathway for bacteria and chemicals to enter the bloodstream.

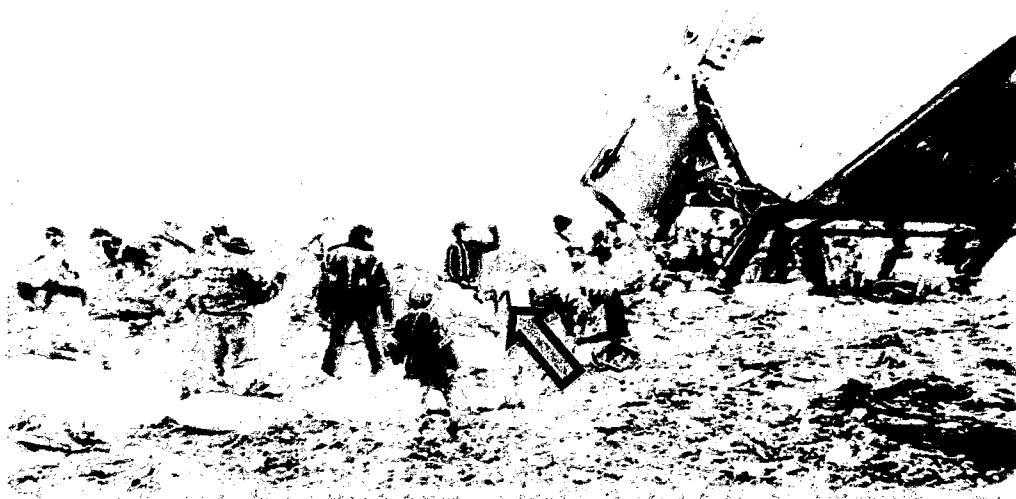


Figure 42. Boy consuming soda found while scavenging municipal waste in Rampa

“Despite the considerable economic and social benefits they produce, waste collectors usually operate in hostile social environments. Public authorities often treat them as nuisances, embarrassment, or even criminals” (WIEGO, n.d.). “The attitude of the formal waste management sector to informal recycling is often very negative,

regarding it as backward, unhygienic and generally incompatible with a modern waste management system” (Wilson et al., 2006, p. 798). However, “The informal recycling sector is often highly skilled at identifying wastes with potential value” (Wilson et al., 2006, p. 801). The following figures, Figures 43-47, demonstrate a variety of the Roma’s skill sets in identifying and sorting the recyclables in Rampa.



Figure 43. Identifying recyclables in Rampa



Figure 44. Sorting recyclables in Rampa by type and for burning

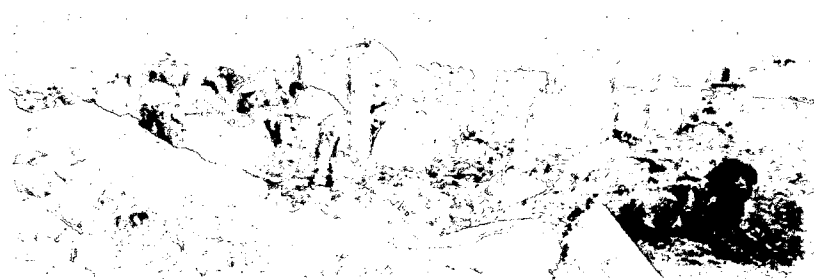


Figure 45. Filling bags with plastic recyclables in Rampa



Figure 46. Packaged recyclables stored in Rampa for collection and sale

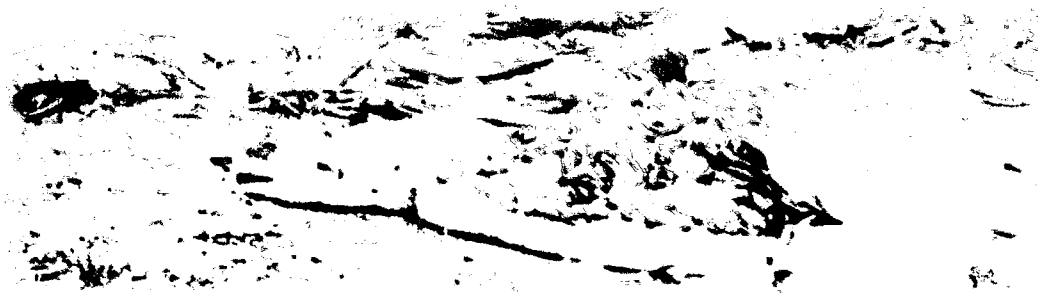


Figure 47. Sorted aluminum and metals in Rampa

Because of the Roma's occupation as scavengers they face a tremendous number of occupational health and safety risks due to the nature of their work and the generally poor working conditions. These include:

- Exposure to elements (extreme temperatures, wind, rain, sun, [snow])
- Exposure to dangerous waste, including toxic substance such as lead and asbestos, as well as blood, fecal matter, animal carcasses, broken glass, needles, and sharp metal objects
- Exposure to diseases transmitted by vermin, flies and mosquitoes
- Back and limb pain, skin irritation and rashes, and specific high risk of tuberculosis, bronchitis, asthma, pneumonia, dysentery, and parasites. (WIEGO, n.d.).

As you can see, the Roma pictured in Figure 48, spend much of their time bent over. It is also common to see people in Dallas holding their backs and at church squirming around in the chair from obvious physical pain.



Figure 48. Roma adults and adolescents scavenging Rampa

Table 8 (from Wilson et al., 2006, p. 803) points out a number of risks, many previously discussed, that the Roma can expect throughout the scavenging processes. These include risks related to the composition of waste, the nature of decomposing organic waste, when handling and processing the waste, and when the waste is disposed.

Table 8

Risk causing factors related to solid waste

Origin of risk factor	Examples of source of possible risk
Composition of waste	Toxic, allergenic and infectious components including gases, dust, leachate, sharps, broken glass
Nature of organic decomposing waste	Gaseous emissions, bioaerosols, dust, leachate, and fine particle sizes; and their change in ability to cause a toxic, allergenic or infectious health response
Handling of waste	Working in traffic, shoveling, lifting, equipment vibrations, accidents
Processing of waste	Odour, noise, vibration, accidents, air and water emissions, residuals, explosions, fires
Disposal of wastes	Odour, noise, vibration, stability of waste piles, air and water emissions, explosions, fires

The occupation of scavenging means contact with a variety of types of waste including both toxic and hazardous wastes. In Romania in 1996, there was little effort to separate hazardous wastes from municipal wastes and even disposal of municipal wastes was inadequate in many communities (Carpenter, Suk, Blaha, & Cikrt, 1996). In addition, according to Eugen Veres, chief executive of Branter-Vere, Cluj has a mere two percent recycling rate (Demian, 2008) therefore, you can only imagine what ends up in the Cluj-Napoca Municipal Landfill. Table 9 (World Bank Group, 2007, p. 2) represents several common types of waste likely to be found in municipal landfills; therefore, providing a better idea of what the Roma are likely to encounter while scavenging Rampa. For example, hospital and other medical waste are a major health hazard. This waste is generated in hospitals, health care centers, medical laboratories, and research centers and includes items like discarded syringe needles, bandages, swabs, plasters, and other types of infectious waste (Edugreen, n.d., p. 1).

Table 9

Sources and types of municipal waste

Source	Typical Waster Generators	Types of Solid Waste
Residential	Single and multifamily dwellings	Food waste, paper, cardboard, plastic, textiles, leather, yard waste, wood, glass, metal, ash, special waste (e.g., bulky items, consumer electronic, white goods, batteries, oil, tires) and household hazardous waste
Industrial	Light and heavy manufacturing, fabrication, construction sites, power and chemical plants	Housekeeping waste, packaging, food waste, construction and demolition materials, hazardous waste, ash, special waste
Commercial	Stores, hotels, restaurants, markets, office buildings	Paper, cardboard, plastic, wood, food waste, glass, metal, special waste, hazardous waste
Institutional	Schools, hospitals, prisons, government centers	Paper, cardboard, plastic, wood, food waste, glass, metal, special waste, hazardous waste
Construction and Demolition	New construction sites, road repair, renovation sites, demolition of buildings	Wood, steel, concrete, dirt, etc.
Municipal Services	Street cleaning, landscaping, parks, beaches, other recreational areas, water and wastewater treatment plants	Street sweepings; landscape and tree trimmings; general waste from parks, beaches and other recreational areas; sludge from water and wastewater treatment plants
Process	Heavy and light manufacturing, refineries, chemical plants, power plants, mineral extraction and processing	Industrial process waste, scrap materials, off-specification products, slag, tailings

We will now leave Rampa and start heading back to the YVM/FAF Center. I will discuss the Roma's environmental health disparities that we have encountered along the way.

Environmental and Occupational Health Disparities

The Roma of Dallas clearly face multiple and overlapping environmental and occupational health disparities that are cause for great concern. Through our observation from the YVM/FAF buildings, our walk-through the community, and our visit to Rampa, you should now have a more nuanced understanding of the environmental health conditions they endure and some of the possible health effects. The next two tables (Tables 10 and 11) will continue this conversation and illustrate a number of health hazards that result specifically from exposure to toxic chemicals, as this is clearly an environmental health concern. The tables are in no way comprehensive but provide further insight into the metals and chemicals residents are likely to be exposed to.

Table 10 (adapted from Agency for Toxic Substances and Disease Registry, 2008) starts out by illustrating multiple exposure routes for a number of chemicals including air/smoke, water, dust, soil, and food. As you can see, most chemicals have multiple exposure routes, making the people of Dallas very susceptible to high risks of exposure. For example, arsenic, copper, lead, and zinc can all expose the Roma through all five pathways. In addition, all chemicals are passed through air/smoke and half of the 14 chemicals listed can pass through soil to groundwater. What makes their situation worrisome is that they are exposed to multiple chemicals therefore creating mixtures of different chemicals in both the contamination source and in their bodies. Very little is

known about the possible health effects from exposure to mixtures of chemicals and the potential interactions of various toxicants (Kerns, 2001).

Table 10

Exposure routes for chemicals likely to be found in Dallas/Pata Rat

Name	Exposure Routes				
	Air/Smoke	Water	Dust	Soil	Food
Arsenic	x	x*	x	x	x
Benzene	x	x*		x	x
Cadmium	x	x*		x	x
Chromium	x	x*		x	x
Copper	x	x	x	x	x
Creosote	x	x*		x	x
Dioxins	x	x		x	x
Hexane	x				
Hydrogen Fluoride	x	x		x	x
Hydrogen Sulfide	x	x			
Lead	x	x**	x	x	x
Mercury	x	x			x
Styrene	x	x			
Zinc	x	x*	x	x	x

*Chemical can pass through soil into groundwater

**Movement into groundwater depends on chemical compound and soil characteristics

Health hazards from both short- and long-term exposures to chemicals, highlighted in Table 11 (adapted from Agency for Toxic Substances and Disease Registry, 2008), are a reality for the people of Dallas, especially the children who are particularly vulnerable to the toxic effects of chemicals, for example, lead. Children are more susceptible to lead poisoning because intake per unit of body weight is higher, they often put objects in their mouths, they are going through rapid development, and

therefore more vulnerable to the toxic effects of lead. There is actually no known safe level in children (European Environment and Health Information System, ENHIS, 2007).

“Lead induced toxicity of the central nervous system causes delayed development, diminished intelligence and altered behavior, especially among children” (Australian Commonwealth Scientific and Industrial Research Center [CSIRO], 2007). Many studies have found that levels over 10pg/dL of blood level can reduce IQ by 1-3 points and more recent studies are showing effects occurring at much lower levels. Cognitive development affects school performance, level of educational attainment, and one’s success in the labor market. The children of Dallas also face neurological problems and poor cognitive development, which are a likely a result of chemical exposures, more specifically lead poisoning. Their developmental problems may be further exacerbated, not only by other chemical exposures, but also by the lack of attention and stimulation they receive at an early age by their parents who are often working long hours at Rampa or lack the resources and/or education to adequately stimulate their children (Dr. Florescu, personal communication, May 2009).

Table 11

Health hazards associated with chemicals likely to be found in Dallas/Pata Rat

Chemical Name	Health Hazards
Arsenic	Breathing high levels causes sore throats and irritates lungs. Very high levels can result in death. Low levels cause nausea, vomiting, decreased production of red and white blood cells, damage to blood vessels, abnormal heart rhythm, and sensation of 'pins and needles' in hands in feet. Ingesting/breathing low levels for long period of time can cause darkening of the skin and appearance of 'warts' on palms, soles, or torso. Skin contact may cause redness and swelling and ingestion may cause diarrhea and kidney damage. Long-term exposure in children can cause lower IQ scores. Can inure pregnant women and unborn babies. Increases risk to skin cancer and cancer in the liver, bladder, and lungs. Known human carcinogen.
Benzene	Breathing high levels can cause drowsiness, dizziness, headaches, tremors, rapid heart rate, confusion, unconsciousness, and death. Eating/drinking contaminated food/water can cause vomiting, dizziness, irritation of stomach, sleepiness, rapid heart rate, convulsions, and death. Long-term exposure has harmful effects on the blood and bone marrow causing a decrease in red blood cells and lead to anemia. Can lead to excessive bleeding, affect the immune system and increase chances for infection. Women breathing high levels for many months experience irregular menstrual periods and a decrease in the size of their ovaries. Long-term exposure to high levels in the air cause leukemia, particularly acute myelogenous leukemia, a cancer of the blood-forming organs.
Cadmium	Breathing high levels can severely damage the lungs. Eating/drinking contaminated food/water with high levels irritates the stomach and leads to vomiting and diarrhea. Long-term exposure to lower levels in air, water, or food can lead to lung damage, fragile bones and build-up in the kidneys and possible kidney disease. Kidney, lung, and bone damage in children. Known human carcinogen.

(table continues)

Chemical Name	Health Hazards
Chromium	Breathing high levels cause irritation to lining of nose, runny nose, nose ulcers, and breathing problems like asthma, shortness of breath, coughing, or wheezing. Skin contact can cause skin ulcers, allergic reactions including severe redness and swelling of the skin. Lung cancer from inhalation and stomach tumors in drinking water.
Copper	Breathing high levels can cause irritation to nose and throat. Ingesting high levels can cause nausea, vomiting, and diarrhea. Very high doses can cause damage to liver, kidneys and even cause death.
Creosote	Eating or drinking contaminated food/water can cause stomach pains and burning of mouth and throat. Brief contact with high amounts, may cause rash or severe irritation of the skin, chemical burns of the surfaces of the eyes, kidney or liver problems, convulsions or mental confusion, unconsciousness or death. Longer exposure to low amounts can result in damage to the cornea, increased light sensitivity, skin damage, and irritation of the respiratory tract. Carcinogenic by IARC and probable human carcinogen by EPA.
Dioxins (2,3,7,8-TCDD)	Chloracne, a severe skin disease, skin rashes, discoloration, and excessive body hair. Liver damage, alterations in glucose metabolism, and subtle changes in hormonal levels. 2,3,7,8-TCDD human carcinogen
Hexane	Breathing large amounts causes numbness in feet and hands then muscle weakness in feet and lower legs. Continued exposure leads to paralysis of arms and legs.
Hydrogen Sulfide	Low concentrations cause irritation to nose, eyes, throat, and difficulty breathing for asthmatics. Exposure to high concentrations (500ppm or higher) can result in loss of consciousness or death. Permanent or long-term effects include headaches, poor memory, poor attention span, and poor motor function.

(table continues)

Chemical Name	Health Hazards
Lead	<p>Main target is nervous system but can affect almost every organ and system in the body. Long-term exposure leads to decreased performance of nervous system functions and may cause weakness in fingers, wrists, and ankles. Causes anemia and small increases in blood pressure. Exposure to high levels can severely damage kidneys, brain and cause death. Can lead to miscarriage in pregnant women and damage sperm production organs in males. Children more vulnerable and may develop blood anemia, muscle weakness, severe stomachaches, and brain damage. Affects mental and physical growth. Unborn children affected by premature births, decreased mental ability, learning difficulties, and reduced growth. Probable human carcinogen.</p>
Mercury	<p>Nervous system is sensitive to all forms. High levels can permanently damage the brain, kidneys, and developing fetus. Brain functioning effects include irritability, shyness, changes in vision or hearing, tremors, and memory problems. Short-term exposure to high levels of vapors include nausea, vomiting, lung damage, diarrhea, skin rashes, eye irritation, and increases in blood pressure or heart rate. Exposure in mother passes to fetus and can accumulate there causing brain damage, mental retardation, incoordination, blindness, seizures, and inability to speak. Children poisoned by mercury can develop kidney damage and problems with their nervous and digestive systems.</p>
Styrene	<p>Breathing high levels may cause nervous system effects including changes in color vision, tiredness, feeling drunk, concentration problems, and balance problems.</p>
Zinc	<p>Harmful effects begin at levels 10-15 times higher than amount needed for good health. Inhaling large amounts of dust or fumes can cause metal fume fever, a short-term disease. No information available for effects of long-term exposure. Ingesting large amounts can cause nausea, stomach cramps, and vomiting. Longer larger doses can cause anemia.</p>

The following images provide a visual account of some of the physical signs and symptoms of health concerns seen among the children in Dallas. In Figure 49, the child has a cold and her nose is caked with mucous. You can see the mucous in and around her nostrils is mixed with soil and appears to have been there a while. This pattern is similar to the child we visited during our journey through Dallas. This exemplifies a route of entry for toxic chemicals through contaminated soil. Another route is actual ingestion through the mouth. The child's teeth, in the same image, shows soil covering their teeth. Both these observations are common among many of the children, in addition to soil/dirt being on their face, in their ears, around their eyes, and embedded around and under their fingernails.



Figure 49. Child from Dallas with runny nose and soil on teeth

Skin rashes, including the staph infection seen in Figure 50, are also a common problem. What makes staph and other communicable diseases worse in Dallas is how easy they can spread.



Figure 50. Child from Dallas with staph infection on chin

Lack of proper hygiene and sanitation increase the risk of spreading skin and other communicable diseases. Additional problems for all ages in the community exist as a result of water scarcity. The combination of water scarcity and poor hygiene and sanitation leads to sicknesses and problems including diarrhea, hepatitis, lice, skin problems/infections like scabies, larger infections due to cuts from lack of first aid, and oral health diseases (Dr. Florescu, personal communication, May, 2009). A more unsettling observation was at least a half a dozen children had eye problems including infections, crossed eyes, lazy eyes, and even blindness, an occurrence that seemed disproportionately high. Figure 51 illustrates one of the observed vision problems in a child, about 10 years old, whose left eye (right side of picture) appeared abnormally lazy and swollen around the eye.



Figure 51. Child from Dallas with abnormal left eye (right eye in picture)

The child in Figure 52, in addition to having a similar lazy left eye as the boy above, likely has an infection or chemical burn to the right eye (left eye in picture). There are white, crusty growths and a painful lesion on her right eye (see red arrows). In addition, there is extreme redness and swelling around both eyes.

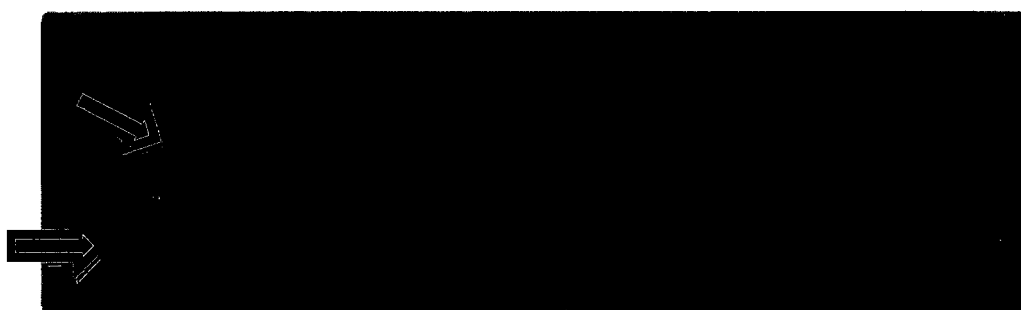


Figure 52. Child from Dallas with swollen eyes, abnormal vision, and a chemical burn or infection in right eye with dried pus in and around the eye (left eye in picture)

In the next image, Figure 53, a young girl of 5-6 has a cyst or growth on her cheek. She is visually in pain and is touching it out of habit with her small fingers. You can see the edge of the downside of her frown and, although not pictured, her eyes were droopy and filled with tears. Upon seeing her, my heart dropped and my stomach sank to the pit of my belly. I could not help but want to do something to ease her pain, but sadly there was

nothing I could do at that moment. I did give her a toothbrush as that was all I had to give.



Figure 53. Child from Dallas in pain with growth/cyst on cheek

Another extremely disheartening sign of disease was found in a young girl of around 10-12 years old. When I first saw her, she was visually unwell and had very sad, tired eyes. She wore an almost permanent frown, yet, what struck me most was when she turned around (see Figure 54).



Figure 54. Child from Dallas with large balding spot on back of head

The young girl was/is balding and has what appears to be a long-term illness, perhaps some form of cancer. Many chemicals like arsenic, cadmium and dioxins found in Dallas are carcinogens and can lead to cancer. Creosote and lead are also probable carcinogens (ATSDR, 2008). In addition to the signs and symptoms illustrated above, the children reportedly suffer from ear infections, sore throats, diarrhea, headaches, asthma, bronchitis, an inflamed appendix, blood tumors, and mental and behavioral problems. In addition to the physical health problems, their future 'life chances' and quality of life does not look good. When 31 households were asked what they predicted for the future for the children, close to 84% (0.839) responded bad, only one replied good, and another replied better. Three chose not to reply. Of the 26 or 84% that responded negatively their answer was one of the following: "don't have words to say," "in misery," "no where," "bad," "no future," "very bad," "difficult," "without a sense," and "better not to see it."

Adults also face a disproportionately high number of health disparities and many feel sick on a daily basis. Headaches, colds, skin diseases, teeth problems, indigestion, eye problems, asthma, difficulty breathing, high blood pressure, diabetes, heart problems, cancer, and problems with stomach, liver and kidneys were all reported as current health problems. In addition, they reported feeling dizzy/vertigo, having chest pains, headaches, pain in their legs and spine, and having problems breathing. Additional illness and poor health were observed in the adults. Women holding their stomachs, men unable to sit for longer than 5-10 minutes from back and leg pain, both men and women gasping for air, people limping, several lazy or wandering eyes, and the constant sound of coughing, both loose and tight, some so bad they were painful to listen to. Their coughs could have been from bronchitis, a possible Tuberculosis (TB) rattle, or chronic obstructive pulmonary disease (COPD). Honestly, it hurts to think about some of them coughing. I actually felt some of their pain when I had a respiratory illness and extremely painful and loud cough for almost seven months following my visit in May 2009. It led me to take a TB test and have lung x-rays. Luckily, my tests came back normal, but I never had a cough that lasted that long before and sounded that loud.

With their occupation as scavengers, the Roma of Dallas and those of all of “Pata Rat” face a number of occupational health disparities in which they are not alone. Scavengers around the world are affected by similar health problems. For example, 96 landfill workers at a municipal solid waste (MSW) open landfill site in India were compared with matched controls and examined for health symptoms. An association was found between occupational exposure, respiratory symptoms, and lung function

decrement. The study concluded that workers at the landfill site suffered from multiple physical and mental health problems that appeared to be occupation-related (Ray, Roychoudhury, Muckherjee, Roy, & Lahiri, 2005). Prevalence rates for upper and lower respiratory symptoms in landfill workers from the study are illustrated in Table 12 (Ray et al., 2005, p. 258) and general health problems faced by the same landfill workers are represented in Table 13 (Ray et al., 2005, p. 259).

Table 12

Prevalence (%) of upper and lower respiratory symptoms in landfill workers

Symptom	Controls (n=90)	Landfill workers (n=96)
Sinusitis	6.7	18.8
Running or stuffy nose	13.3	31.2*
Sore throat	16.7	18.8
Common cold and fever	26.7	50.0*
Frequent sneezing	6.7	58.3*
Headache	13.3	39.6*
Dry cough	13.3	34.3*
Cough with phlegm	26.7	37.5
Wheezing breath	6.7	12.5*
Chest discomfort or pain	20	41.7*
Breathless on exertion	30	39.6

Results are expressed as percentage of individuals with symptom.
More than one symptom was found in many cases.

Table 13

General health problems in landfill workers

Symptom	Control	Landfill worker
Gum infection	5.5	15.6*
Palpable liver	6.7	22.9*
Diarrhea	6.7	35.4*
Palpable colon	3.3	16.7*
Fungal infection	6.7	22.9*
Cuts/pricks	2.2	35.4*
Ulceration	0	6.2*
Blurred vision	6.7	19.8*
Burning sensation in extremity	10	64.6*
Tingling / numbness	13.3	60.4*
Transient loss of memory	20	37.5*
Depression	23.3	43.7*
Irritability	33.3	52.2
Vertigo / dizziness	23.3	36.4

Results are expressed in percentages of individuals

*p<0.05 compared with controls in x2-test

We are almost to Dallas now and will soon be back to the YVM/FAF New Life Education Center where we can call a taxi. As we return down Pata Rat Road, the sun is setting and the Roma people are out and about. Many children and youth are playing in the streets and paths and young adults are hanging out, talking, and smoking by the collection center. Several of the kids join us, some holding our hands and others just walking alongside. Four boys are playing soccer and several children are running up and down the street. A couple of kids are pretending to be a horse and wagon with debris they have found while another boy rolls a tire down the street. As dinner is prepared in

Dallas, small smoke clouds roll up from the stoves; carrying the smells of cabbage, sausage, and French-fries through the air. A catchy musical tune that makes you want to dance plays out from one of the houses. It is loud enough for the whole community to hear, and for us to enjoy as we walk by. All we have seen here today is part of the Roma of Dallas' life. This is their reality; at least one version of their reality told from an environmental health perspective.

Conclusion

On the last day of my research, Pastor Rufus, Founder and Director of the Yielded Vessels Ministry/Family Aid Foundation led a closing thank you for me in front of approximately 100 Roma community members and international visitors. His theme was difference. He told them I was different, different than the past researchers and organizations who have come through "Pata Rat." I was different because I had come to Dallas to learn from them, not just about them. More importantly, I was going to do something with what I learned. I was going to analyze the information I gathered and find out ways in which their quality of life could be improved. This truly was my aim and I hope that the participatory nature and innovativeness of this study and representation will open up new doors and spark new debates. It is my intention to encourage and influence people who have the ability and resources to take responsibility and action where it is needed most. If they do, the Roma's quality of life and 'life chances' have the opportunity to improve, the environmental and occupational disparities they have been forced to endure can be diminished, and some form of social and environmental justice can be served.

In the following chapter, conclusions and recommendations are made to help lead and guide future directions for working with the Roma of Dallas and Roma communities like them throughout Romania and across Central and Eastern Europe.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

The previous chapter provided an illustrative narrative of the environmental and occupational disparities the Roma of Dallas face on a daily basis. It is clear they are living in “survival” mode. In other words they are living and working to survive each day. A major problem with this way of life is that their living and working conditions are inhumane and detrimental to their health, well-being, and future ‘life-chances.’ It can be concluded from the findings in this study that the Roma of Dallas and all of “Pata Rat” are deprived of a number of basic human rights and face both social and environmental injustices. This final chapter will discuss these conclusions and provide a number of recommendations that, if implemented, would not only improve their environmental and occupational health, but would also help in restoring the Roma’s status to ‘us’ from their previous status of the ‘Other.’ Conclusions and recommendations are based on (1) Human Rights, (2) Community Rights, (3) Environmental Justice, (4) Future Research Outreach, and (5) Social Justice.

Human Rights

The UN Convention on the Rights of the Child (CRC) is “the most universally accepted human rights instrument in history” and has been ratified by nearly every country in the world including Romania (United Nations Children’s Fund, n.d.a.). Because the children in Dallas are clearly the most vulnerable subgroup, the CRC is an appropriate point of reference to further this analysis because it places children at the center of the quest for international human rights standards. It was also one of the first

international treaties to incorporate civil, political, economical, social, and cultural rights (Human Rights Resource Center, 2000). The following articles are emphasized as directly affecting the children of Dallas. A fact sheet developed by UNICEF describing all the articles can be found in Appendix F (United Nations Children's Fund, n.d.b.).

- Article 6 – Right to Survival and Development
- Article 7 – Right to Name and Nationality
- Article 8 – Right to Preservation of Identity
- Article 9 – Right to Health and Health Services
- Article 27 – Right to an Adequate Standard of Living
- Article 28 and 29 – Right to Education
- Article 30 – Right to Cultural Identity
- Article 32 – Protection from Economic Exploitation and Dangerous Labor

Adults are also denied several basic human rights. Highlighted here are selected articles from the Universal Declaration of Human Rights, found in Appendix G, that currently most affect the Roma people of Dallas. They are Articles 15, 23, and 24. While there are additional articles that apply to the Roma's current situation, these are the most important and critical for addressing their most immediate and dire needs in relation to their environmental and occupational health conditions. First, they have the "right to a nationality" (Article 23). In addition to the right that "No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality." "Establishing and preserving an individual's right to nationality is a necessary prerequisite for the expansion and enforcement of all other human rights" (Frelick & Lynch, 2005, p. 23).

Next, the Roma of Dallas have the right to work, but more importantly they have the right to work among safe and favorable conditions (Article 23). Working in Rampa presents in a number of occupational health hazards and leads to their stigmatization as dirty scavengers, thus further exacerbating their human dignity and marginalization. According to the Declaration, the Roma, especially those at the lowest level in the informal recycling sector hierarchy, have the right to work that ensures the worker and their family have “an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.” A third basic human right found in Article 24 is specifically related to the Roma’s environmental health conditions in Dallas and states that everyone has the right to an adequate standard of living. More specifically, Article 24 states:

1. Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing, and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age, or other lack of livelihood in circumstances beyond his control.
2. Motherhood and childhood are entitled to special care and assistance. All children whether born in or out of wedlock, shall enjoy the same protection.

Community Rights

In addition to their basic human rights not being met, the ‘community’ of Dallas lacks basic community rights. First and foremost, Dallas needs to be recognized, treated, and respected as a community. This aligns with what Brown (2003) asserted as a main

component of community-based participatory research in environmental health, which is to define the community as a unit of identity, in this case Dallas. Studying and applying regulations at the community level is important and aligns with the language used in environmental policy and human rights of the European Union. An example of the impact of community in environmental policy came about in the 1987 Single European Act. Changes made a significant impact on environmental policy approaches. These changes resulted in a new title, Title VII (Articles 130r-130t), that set community environmental policy goals and made the environment the central concern of the community. Article 130r (now 174) states the following four objectives for community policy on the environment:

- To preserve, protect and improve the quality of the environment;
- To protect human health;
- To be prudent and rational with utilization of natural resources; and
- To promote measures at international level to deal with regional or worldwide environmental problems.

Outlined below are select articles from Part II of the Draft Declaration of Principles on Human Rights and the Environment (1994) on Community Rights (McCormick, 2001). The Declaration is the first international instrument to fully address the linkage between human rights and the environment. The articles are highlighted here to introduce several rights that are not being met for the community of Dallas. They are:

- Article 8: Right to Living Environment Free From [Industrial] Hazards
- Article 9: Right to Environmental Information
- Article 10: Right to Community Participation
- Article 11: Right to Environmental Monitoring
- Article 12: Right to Community Education
- Article 13: Right to Community Emergency Preparedness Procedure
- Article 14: Right to Enforcement of Environmental Laws

The full Declaration is found in Appendix H (Environment and Human Rights Advisory, 2008; McCormick, 2001).

Environmental Justice

The combined crisis of health issues, human rights, and environmental conditions is now often known as environmental justice (Steger & Filcak, 2008). At a workshop in Budapest, Hungary, environmental and human rights organizations defined environmental justice as “the fair treatment of people regardless of ethnic origin or class in the distribution of negative environmental consequences from development plans and policies, industrial operations, or natural disasters and as fair access to natural resources and a clean environment” (p. 49). It is also “the recognition and involvement of stakeholders regardless of their economic status or ethnicity in development, implementation, and enforcement of policies, programs and projects related to the distribution of environmental benefits” (Steger & Filcak, 2008, p. 49). With these definitions in mind, there are several recommendations for bringing environmental justice to the Roma people of Dallas: (1) Improve their community environment with needed

environmental services, (2) Improve the occupational health and safety conditions in Rampa, and (3) Develop a Roma Recycling and Development Organization.

Community Environment and Development

The following environmental services should be implemented, and done in consultation with significant Roma participation and oversight, including participatory administration: sanitation services, clean water supply, hygiene promotion, air pollution control (both indoor and outdoor), storm water drainage, solid waste management, hazardous waste management, vector control, and occupational health and safety management. More specific community development recommendations include the following:

- Allow Dallas or nontoxic area of land nearby to become a permanent land for the Roma that choose to live there.
- Recognize Dallas as a 'community' or 'village' and work with community members to decide on their community name.
- Make an additional map with community members that include street names and house numbers.
- Provide city services to Dallas including waste pick-up, postal services, sewage, water, electricity, etc.
- Hire a Roma Health Mediator or other mediator for the community to assist with obtaining proper documents and citizenship.
- Increase health services offered in the community (i.e., number of days, number of hours, types of physicians/services/specialists).

- Provide additional educational services and support for children and adults.
- Provide clean-up and waste removal services.
- Work with community members to clean up their community.
- Make rules and assign roles together with community members and YVM/FAF to maintain the community's cleanliness.

In addition to having the Roma from Dallas' participation, it is recommended that the YVM/FAF staff and volunteers be included in area planning and developments. Having worked in "Pata Rat" since 1997, staff and volunteers have gained trust and have a positive influence among many community members. To assist the YVM/FAF in better serving the local Roma, more funding and resources are needed. Funding is required, not only for improving the Roma's environmental health conditions, but also for their personal and professional development, especially the children. Pregnant mothers and children are in need of a nutritional food program, which YVM/FAF wants to implement. YVM/FAF staff has also expressed interest in identifying and providing support for leaders to represent the communities in Parliament. Moreover, given the necessary resources, staff members would be enabled to increase their programs and better reach the needs of the local Roma.

The Yielded Vessels Ministries/Family Aid Foundation delivers a variety of programs in multiple locations with very limited staff and volunteers. Funding would enable the organization to hire additional staff to increase their efforts in "Pata Rat" with expanded health, nutritional, environmental, educational, and developmental programs. Funding and grants should also be awarded to the community-based organization so they

can expand their programs by building an additional community center for a feeding program and for providing additional development programs. Monetary support should be provided by foundations, governments, and grant-making organizations working to improve the Roma's situation across CEE. Funding streams are currently available and it is highly anticipated that additional prospects will emerge, as the Romania government implement's the Decade for Roma Inclusion and transitions to European Union policies. Assistance in preparing the grants should be provided by local nonprofits, the academic community, or volunteers with the skills and resources to do so.

Occupational Health and Safety

Occupationally, "immediate steps should be taken by all concerned to introduce appropriate preventive measures to safeguard the health of the persons working at the landfill sites" (Ray et al., 2005, p. 261). Cointreau (2006) recommends the following general work arrangements:

- Provide clean drinking water and sanitation facilities.
- Vaccinate for hepatitis A and B, tetanus, diphtheria, polio, typhoid, and in endemic areas encephalitis. For workers at landfills, consider rabies.
- Develop medical surveillance standards, including baseline and follow-up medical examinations [e.g., overall fitness and strength, heart condition, pulmonary function, allergies/asthma, vision, auditory acuity, hepatic and renal function, standard clinical laboratory tests (e.g., CBC, SMA-22 biochem profile), vaccination and disease history, surgical history, musculoskeletal condition, sensitivity to heights or claustrophobia, vertigo/dizziness, incidence of seizures,

etc.], routine survey of workers about job tasks performed and their physiological responses to their job tasks.

- Provide protective clothing with highly visible colors, shoes/boots and gloves.
- Provide a place to wash with soap before eating, smoking, or going home.

(Ideally, workers will have change of clothing before leaving site and going home or taking public transport).

- Provide training on value of good hygiene and first aid.
- Develop occupational and environmental health training materials on and injury issues for all staff at all levels related to solid waste management. (pp. 36-37)

Like community environmental services, these occupational health and safety recommendations should be done with local Roma's input and that facilitate participatory administration. Moreover, they should facilitate and support the development of a Roma Recycling and Development Organization, that would not only improve their physical, social, and built environments, but would lead to increased awareness of Roma environmental and occupational health issues across CEE.

Roma Recycling and Development Organization

It is also recommended that a scavenger organization from "Pata Rat" be formed and supported so they can work with stakeholders for the future ecological landfill that has been proposed by the European Union. "The good news is that, when organized, waste collectors can and do raise their income, their social standing, and their self esteem" (WIEGO, n.d.). It is recommended that the EU, the Romania government, and stakeholders in the development of future MSWM programs in Romania actively involve

Roma scavengers in the planning process, particularly those from Dallas and “Pata Rat.” “The preferred option is to integrate the informal sector into waste management planning, building on their practices and experience, while working to improve efficiency and the living and working conditions of those involved” (Wilson et al., 2006, p. 797). EU and MSWM plans should take into account the livelihoods that are centered on the informal recycling sector in Romania and other CEE countries. Simultaneously, it is essential that EU and Romania governments enforce policies that take into account the lives and contributions of the Roma. In the case of “Pata Rat” representatives from the government should be actively working with community members and preparing the local Roma scavengers for transition to a new waste management system. The following is a list of common demands made by waste collector organizations that provide a starting point for the needs of “Pata Rat” (Women for Informal Employment: Globalizing and Organizing-WIEGO, n.d.):

- Identification, recognition and registration (Identity Cards).
- Right to work and have access to waste.
- Provision of facilities for collection and sorting of waste – sorting sites without harassment.
- Provision of sites to sell waste (“cash for trash”).
- Sanitary and storage facilities.
- Health care and social security provisions.
- Credit / loan facilities.
- Granting of rights to collect waste for recycling (linked to ID cards).

- Organization of house-to-house collections through waste collector organizations.
- Priority employment for waste pickers to preserve their livelihoods.
- Consultation / negotiation between waste collector organizations and waste collectors before initiating any new solid waste disposal plans.
- Provision of rest rooms and drinking water at landfill sites.
- Prohibition of child labor.
- Institutionalization of informal waste collection at doorstep/other collection sites.
- Encouragement and support for waste collection organizations, both financial and nonfinancial.

To best facilitate a Roma Recycling and Development Organization and Roma stakeholders in the MSWM planning process, more research and outreach is needed and recommended. Continuing and building on the established academic-community relationship is pertinent and provides a framework for continued and future community-based participatory research in environmental health.

Future Research and Outreach

It is recommended that additional research, both qualitative and quantitative, be implemented in Dallas. Both should be done with careful consideration of the historical, social, cultural, political, and environmental dimensions that affected the position of the Roma in society today. Additional participatory qualitative research should look deeper into the Roma's history and their current struggles, health, and quality of life. Furthermore, conversations and focus groups with community members on ways to improve their community environment and future 'life chances' is needed. This includes,

but is not limited to, finding out their skills and desires for future employment opportunities.

On another note, more qualitative research is also recommended and needed to uncover the social injustices and exploitative behaviors that are occurring within Dallas and the Roma population themselves. Domestic abuse, alcoholism, community violence, child neglect, and economic exploitation were all identified issues within the community; however, they were beyond the scope of this research study. Roma women, children, the sick, and the elderly in Dallas are amongst the most vulnerable, and shared stories of abuse and exploitation. It is important that future studies explore these components and further investigate the social problems within the community. It is imperative that this type of research is done in a sensitive and strategic way, one that is careful not to further harm or marginalize them.

Quantitative sampling and testing should be done of the soil/dirt, dust, water, soil gas emissions, and air in multiple locations in Dallas and at Rampa. Epidemiological studies are also important and will contribute to the understanding between the relationship between health and the environment and are important to the reality of the Roma's health status and the developing world (Heller, 1998). In addition, biomedical monitoring for blood lead levels and other metals/chemicals/toxins is recommended because of the Roma's close proximity and prolonged exposure to toxic metal and chemicals. Table 14 (adapted from Agency for Toxic Substances and Disease Registry, 2008) points out several of the chemicals people in Dallas are likely to be exposed to and methods for testing exposure levels.

Table 14

Available medical tests for biomedical monitoring for chemicals likely to be found in above average levels in the people of Dallas/Pata Rat

Name	Medical Tests					
	Blood	Urine	Hair	Nails	Bone	Other
Arsenic	x	x**(few days)	x (6-12 mths)	x (6-12 mths)		
Benzene	x (recent exp. only)	x (recent exp. only) not reliable			x (shortly after exp.)	
Cadmium	x (recent exp. only)	x** (rec & past exp.)	x	x		
Chromium	x	x	x			
Copper	x	x	x	x		other tissues
Creosote	x (after exp.)	x (after exp.)				body tissues
Dioxins	x					body fat (stays for long time), breast milk
Hexane		x(2-3 days)				
Hydrogen Fluoride		x (after exp.)			x (long-term exp.)	
Hydrogen Sulfide		x (thiosulfate levels)				exhaled air (w/in 2 hours)
Lead	x (amount & rec. exp.)				x	teeth
Mercury	x (metallic, organic, methyl)	x (metallic or organic)	x (methyl-mercury)			

(table continues)

Name	Blood	Urine	Hair	Nails	Bone	Other
Styrene	x (w/in 1 day)	x (w/in 1 day)				body tissues (w/in 1 day)
Zinc	x** (rec. exp.)	x	x		x (shortly after exp.)	feces**(rec. exp.), saliva

x test is available

** test is proven reliable regarding exposure, not whether harmful health effects will occur

() notes regarding test reliability or chemical it tests for

If or when biomedical monitoring takes place with the Roma of “Pata Rat,” the ‘International Ethical Guidelines for Biomedical Research Involving Human Subjects’ should be adhered to. The set of guidelines was prepared by the Council of International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO) and is available in Appendix I. More importantly, it is imperative that any research and tests that are implemented with the Roma provide immediate impacts or incentives for the participants involved. Research and biomedical monitoring should not be done for the sole purpose of gathering data or publishing an article without the research in some form benefiting the participants. Furthermore, the work that is done should be used to help develop concrete plans that will help reduce future toxic exposures. This recommendation extends beyond “Pata Rat” to all future research done with Roma and marginalized populations around the globe.

For medical students and future researchers working in “Pata Rat,” it is recommended that the maps of Dallas made by community members be used during the

sampling process. They provide a layout of the community that will enable researchers to identify where their participants are and also prevent duplication. They also identify the major components of the built environment that aid in locating important areas of investigation, for example their water sources. At base, the maps provide a way to organize the community for improved data collection. The cartographic representations also identify Dallas as a community and should remind medical students/researchers that they are working with people who are living in a community that they call home.

The academic community should also continue to utilize its vast amount of resources to implement intervention and educational programs that aim at improving both environmental and occupational health and safety. For example, as part of the annual UNI Study Abroad Program that provides outreach for the Roma of “Pata Rat,” a focus could be placed on communicating risks and focusing on behavior changes that would decrease exposures and risk associated with lead and other chemical poisoning.

Promotion activities could include the following:

- Teach about reducing lead and chemical exposure by proper hygiene (Distribute hygiene kits with tea).
- Teach children specific things they should not play with (i.e., shiny silver liquids, thermometers, batteries, etc.).
- Teach how to reduce chemical exposures to parents by teaching about protective clothing and washing clothes and self before going home around children. (Distribute gloves, other protective wear to adults, laundry soap, and other soap that ‘cuts the grease’).

- Teach parents to restrict children's access to solid waste piles and contaminated soil.
- Teach the importance of frequent wet mopping to control contaminated dust in the homes.
- Teach parents what to do when exposed to hazardous waste or chemical burns (e.g., eye flush).
- Teach children to stay away from open burning/smoke or wear mask.
- Teach how to make a small mask with a shirt or mouth/nose covers for burning. (Distribute masks).

It is recommended that the UNI/UMF annual outreach program continue and also expand on its past and current programming by developing a guide for environmental health promotion for Roma and marginalized populations. The guide should include information about the local people and community in addition to environmental health promotion activities. Additionally, it is recommended that the program expand to include more community-based research opportunities for graduate students. Information from the present study could assist in developing a framework and/or model for implementing community-based participatory research in environmental health, more specifically for Roma populations. The participatory and community-based nature of this study, which considers multiple dimensions, enables future researchers and development workers methods for uncovering more nuanced understandings of environmental health conditions affecting the people they are working with.

A field guide for community-based participatory research in environmental health should be created that provides information on how to implement multiple types of participatory methods, provides information on how to modify the methods to fit the needs of the population under investigation, and includes a variety of community assessment tools like the structured observation questionnaire, the community mapping activity description, and the household survey used in this study. Moreover, these tools and additional assessment tools like them can be utilized for other marginalized and refugee communities around the globe. For example, the structured observation tool provides an environmental health assessment tool for knowing what to look for and identify in communities upon arrival. The household questionnaire also serves as a starting point in uncovering migration patterns and information about personal, family, community, and environmental health. The guide, with supplementary assessment tools, would provide innovative and participatory ways way to gather data that aim to understand rather than explain. Instead of making marginalized people the subject of our conversations, we should invite them to participate and treat them as a voice in the conversation (Rorty, 1979).

For researchers, organizations, and governments to best work with the Roma in ways that are culturally competent and sensitive to their environmental health conditions, there must be attention to social justice. This can be done by inclusion policies, such as including them in future MSWM plans, viewing them as stakeholders, and implementing participatory research and outreach. In addition, social justice can be achieved individually in the way people think of the Roma. By seeing the Roma as part of “us”

and not the “Other” is a start. What is needed is to get beyond the stereotypes and be more mindful of the social world we live in (Schwalbe, 2001).

Social Justice

Being aware of the patterns that make the world what it is enables us to change the world. (Schwalbe, 2001, p. 101)

Being labeled an outsider, a “Gypsy,” and seen as a “whole” or stereotype is not an accurate portrayal of how the Roma see themselves, rather it is a reflection of how outsiders see them (Fonseca, 1995). At base, the Roma are people. They are human beings who have the same basic needs and who suffer, love, fear, dream, and hope as we do. They are also people who feel pain, affection, hate, and gratitude. These comments came from Butler’s observation of whites’ general inability to fully appreciate the ‘Other’ (as cited in Magubane, 2004). What more researchers and people in general need to do is recognize the likeness in people as human beings. The dichotomies, the either/or, the black/white, the superior/inferior, the us/other, etc. need to stop and justice needs to be served.

Although Roma people and communities are not homogeneous and should not be viewed as such, there is a commonality among them. What brings them together is their ‘legacy of struggle’ which is a shared experience of two contradictory worlds (1) privileged and oppressive, and (2) exploited and oppressed (Collins, 2009). It is evident that the Roma of Dallas’ social and environmental injustices are shared across transnational lines. By investigating the commonality or ‘legacy of struggle’ of Roma populations, researchers, social scientists, environmentalists, and social activists are

enabled to see the patterns of social, environmental, and occupational health disparities shared by Roma populations.

Before concluding this final chapter, I would like to employ a standard rhetorical device, similar to what writers of abolitionist tracts used for the emancipation of slaves. They would ask white readers to imagine themselves in the position of the enslaved. “Their intention was to position the white body in the place of the black body to make their suffering visible and intelligible” (Hartman as cited in Magubane, 2004, p. 102). With this in mind, I would like to ask you to be sociologically mindful for a minute and put yourself in the Roma’s shoes. Better said, at least for the first scenario, to put yourself in the Roma’s tattered, mismatched socks. Keep in mind the multi-layers of the Roma of Dallas’ lived reality and what you have read and seen up to this point.

Elderly Woman

You are 81 years old. You only have one of your front top teeth left, but a smile that lights up the room. For the last three years, probably even much longer, your heart feels like it is going to burst out of your chest. Your heartbeat is so rapid and gives you the jitters...and every couple minutes you have to gasp and pull for air. You never feel like you have enough air and the constant palpitations are just too much. The other day you were hospitalized for several days. They put a pacemaker on you but you are really not sure how it works. Worse, because of your health and old-age, you are unable to work; therefore, you have to beg others for food, clothes, and other necessities. You have a large cut on your right front big toe that is infected and sticks out of your tattered, mismatched sock.

55-Year-Old Man

You are a 55 year-old male and have lived in “Pata Rat” for 15 years. You have worked many years of long hours scavenging the Rampa landfill, almost every day until about six months ago. This year you are no longer able to work because you are in too much pain. It is so bad you can hardly sit down. The lower part of your back feels as if it is on fire and you have to get up every 5-10 minutes to walk around. Sometimes, if you sit too long, your legs start falling “asleep.” You have no pain medicine and the doctor only comes once a week. You are lucky if you get a chance to meet with him, since he only comes for three hours and it is first come, first serve. Since you cannot work anymore you have to depend on community members, friends, and the Yielded Vessels Ministries/Family Aid Foundation for food. You are lucky to get enough to eat and sometimes you do not eat at all. Sometimes you do not know what is worse, the pain in your back and legs or the hunger pains. On another note, you have an amazing smile, the kind that makes other people smile just by looking at you. It does well to cover up your pain, although the crinkles in your forehead, holding of your back, moving around, stretching, and continuous walking around all give it away. The other day you had to call the ambulance because it was the only way you could get health care. You thought you were having a heart attack. Luckily, it was “only” really high blood pressure.

Young Mother

You are a young mother of less than 20 years with two children, a one-year old and a three-year old. You spend all of your time in Dallas caring for your children. You cannot go anywhere because you do not have any money. Your husband scavenges

Rampa and is an alcoholic. The little money he makes usually goes to buying beer and cigarettes. Most of the time you eat bread and sometimes, when you are lucky, you get leftovers from your neighbors. Your children are hungry and sick all the time and sometimes all you and your children eat during the day is “air.”

These scenarios hopefully deepened your sociological mindfulness to the injustice of the Roma’s situation. For the Romanians and others who are hindering the progress of the Roma people and their inclusion, Law Professor Hayman (1998) argues that the real tragedy is that we should know better.

- We should know that the biological differences among groups of people are trivial, and that the salient differences are generated through the processes of social interaction.
- We should know that our markets reflect the preferences of the people who have structured and maintained them, and that these biases- structural and unconscious- constitute the real discrimination.
- We should know that unequal outcomes- in education, in employment, and yes, on tests of smartness- reflect the cumulative advantages and disadvantages of centuries of discrimination, and the same biases that pervade all of our culture.
- We should know that our laws and traditions are only what we choose to make them, and that equality can be as real as we dare. (Hayman, 1998, p. 20)

Conclusion

The stigmatization of the Roma began decades ago through policies and carried over to this day through the social constructions of race, low-class status, profession, and stateless/nationless state. Despite this, the Roma have proved to be “survivors.” They have “survived” persecution, slavery, the Holocaust, direct racism, discrimination, and oppression. Their “survival” is no different today. The Roma people and the community of Dallas provide an illustrative example of how the Roma are continuing to survive in socially and environmentally unjust conditions, inhumane conditions that an ‘average’ or ‘normal’ person, a person like you and me, would find intolerable. That is what their environmental conditions are, intolerable. Most are sick, living in misery, and their future ‘life-chances’ are slim to none, especially the children, who sadly do not even realize their predicament. The point I want to make is that they are people, like you and me, with the same basic needs, desires, and rights. What makes them different is that we have ‘life-chances,’ because we have our basic needs and rights met, and we are encouraged and supported to participate in society. That said, the Roma people of Dallas are people who are in desperate need of justice to be served.

For justice to truly be served for the Roma people of Dallas and “Pata Rat,” the international community needs to step in and demand that their human and community rights be met. In addition, any future programs and research implemented on their behalf needs to fully take in account the historical, political, social, and cultural dimensions that have led to their inhumane place in society. More importantly, programs and research need to encourage and support the Roma’s participation in the whole research process

and in society itself. This need for participation goes for all future programs and research with Roma across Romania and Central and Eastern Europe. Without the Roma's perspective and participation, the risk for continued injustice remains high.

In closing, I hope this study, through its innovative representations and inclusion of the Roma's 'voice' or perspective, has made you more sociologically mindful. In other words, I hope you have gained a more nuanced understanding to the injustice that the Roma of Central and Eastern Europe and scavenging communities like Dallas face. With this, I hope new doors of debate will open, new types of research will emerge, and new types of programs will begin, all that in some way truly benefit the Roma people.

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APPENDIX A
FIELD RESEARCH SCHEDULE

	Fri 5/15	Sat 5/16	Sun 5/17	Mon 5/18	Tues 5/19	Wed 5/20	Thurs 5/21	Fri 5/22	Sat 5/23
8:30									
9:00									
9:30									
10:00									
10:30									
11:00									
11:30									
12:00									
12:30									
13:00									
13:30									
14:00									
14:30									
15:00									
15:30									
16:00									
16:30									
17:00									
17:30									
18:00									
18:30									
19:00									
19:30									
20:00									
20:30									

Research
Planning
Meeting
at FAF
Office

Mtg with
Dr. Zeman
and FAF
Staff

FAF Sun
Service,
Research
Intro,
Informed
Consent,
Observation

Prepare
for Intro,
Mapping

Research
Planning
Day

Preparation
for
mapping,
household
surveys

Walk
Through,
Student
Outreach
Day 1

Walk
Through,
Student
Outreach
Day 2

FAF
Thursday
Service,
Home visits
w/ FAF,
Walk-
Through,
Photovoice,
Observation,
Public Bus
System to
Cluj

Reflection,
writing,
photo
develop-
ment

Household
Interviews,
Walk-
Through,
Observation

FAF Youth
Group,
Pizza Party,
Community
Mapping

Community
Mapping,
Walk-
Through

FIELD RESEARCH SCHEDULE

	Sun 5/24	Mon 5/25	Tues 5/26	Wed 5/27	Thurs 5/28	Fri 5/29	Sat 5/30	Sun 5/31
8:30								
9:00								
9:30								
10:00								
10:30								
11:00								
11:30	FAF Sunday Service, Observation				FAF Thursday Service, Rampa Photovoice, Interviews, Observation			FAF Sunday Service, Closing, Thank you, Photo Distribution, & Good-byes
12:00								
12:30								
13:00								
13:30								
14:00								
14:30		Household Interviews, Walk-Through, Observation	Household Interviews, Walk-Through, Observation	Reflection, writing, photo development	Photovoice Follow-Up Activity		Reflection, writing, photo development, prep for closing	
15:00								
15:30								
16:00								
16:30					FAF Youth Group, Mici Party, Follow-Up Mapping, Photovoice Activity			
17:00								
17:30								
18:00								
18:30								
19:00								
19:30								
20:00								
20:30								

APPENDIX B

STRUCTURED OBSERVATION QUESTIONNAIRE
FOR ENVIRONMENTAL HEALTH ASSESSMENT

Community name: _____

Location: _____

Number of households in community: _____

Number people affected: _____

Water

1. What are the types of available water sources?

- _____ well
- _____ spring
- _____ reservoir/dam
- _____ rain water
- _____ seasonal pond
- _____ public stand post/tap/fountain
- _____ hand-dug well
- _____ drilled or driven well
- _____ other – please specify _____

2. How many of each type of water source are available?

- _____ well
- _____ spring
- _____ reservoir/dam
- _____ rain water
- _____ seasonal pond
- _____ public stand post/tap/fountain
- _____ hand-dug well
- _____ other – please specify _____

3. What is the total number of water sources? _____

4. Describe each water source. *Mark table appropriately*

Water Source	Above or Below Grade	Covered yes / no	Grouting yes / no	Casing yes / no	Casing Material yes / no	In Pit yes / no	Standing Water In Pit yes / no
1							
2							
3							
4							
5							
6							

5. Is there stagnant water near the water source (s)? *yes / no* If yes, what is the approximate size of the area (s) of water compared to the size of a car tire?

_____ water source #1 _____ # of tires
 _____ water source #2 _____ # of tires
 _____ water source #3 _____ # of tires
 _____ water source #4 _____ # of tires
 _____ water source #5 _____ # of tires
 _____ water source #6 _____ # of tires

6. Please describe any additional observations regarding the water sources

_____ water source #1 _____
 _____ water source #2 _____
 _____ water source #3 _____
 _____ water source #4 _____
 _____ water source #5 _____
 _____ water source #6 _____

7. Is solid waste observed near the water source(s)? *yes / no* If yes, what are the types of solid waste observed?

_____ animal feces *indicate type(s) of animal* _____
 _____ adult feces
 _____ infants-children under 5 feces
 _____ refuse / garbage
 _____ other _____

8. Is wastewater observed near the water sources? *yes / no* If yes, what is the probable source?

- ☐ water from cleaning
☐ water from bathing
☐ water from cooking
☐ water runoff
☐ water from latrines
☐ other _____

9. On average, how far are water sources from people's homes?

Water source	Distance
<input type="checkbox"/>	(a) less than 25 meters
<input type="checkbox"/>	(b) 25-50 meters
<input type="checkbox"/>	(c) 50-100 meters
<input type="checkbox"/>	(d) 100-200 meters
<input type="checkbox"/>	(e) 200-500 meters
<input type="checkbox"/>	(f) over 500 meters
<input type="checkbox"/>	(g) over 1km

10. What activities take place at or near the water source?

- ☐ washing water containers
☐ washing clothes
☐ bathing/washing self
☐ watering animals
☐ drinking water
☐ recreation / leisure
☐ other _____

11. Is water treated at the source, and if so, how?

- ☐ by filtering with a piece of cloth
☐ by chlorination
☐ by other means _____

12. Which household members collect water?

- ☐ women
☐ men
☐ children

13. How is water transported from the source to the home?

- ☐ plastic container
☐ bucket
☐ metal container
☐ other (specify) _____

14. Do people distinguish between water used for drinking and water for other uses?
 yes / no If yes, what evidence is observed?

15. Are the drinking water containers clean? (free of dirt and substances) yes / no

16. Are drinking water containers sufficient in numbers? yes / no

Food Storage and Handling

What foods do you observe being consumed?

What observations did you make about the preparation of food?

What observations did you make about the storage of food?

Does the household use a drying rack for kitchen utensils? yes / no

Sanitation

1. Where do people defecate?

- ☐ family latrines
☐ community latrines
☐ public restrooms
☐ in nearby field

2. How many total latrines are there (do you see) in the community? _____

3. How many households share the latrine (s)?

Latrine #1 _____ # households
 Latrine #2 _____ # households
 Latrine #3 _____ # households
 Latrine #4 _____ # households
 Latrine #5 _____ # households
 Latrine #6 _____ # households
 Latrine #7 _____ # households
 Latrine #8 _____ # households

4. Which members of the household, community use the latrine?

_____ children under 5 years (boys or girls)
 _____ boys
 _____ girls
 _____ men
 _____ women

5. How many houses have latrines? _____

6. Where are the latrines located? (Indicate reasons why, if relevant)

_____ inside the community
 _____ outside the community
 _____ inside homes

7. Observe the latrines.

_____ Do they have sound superstructure?
 _____ Is the floor safe to stand on?
 _____ Does it have a slab?
 _____ Is the hole small enough to be safe for children?
 _____ Does the latrine provide adequate privacy?
 _____ Any other features? _____

8. Are the latrines in use?

- ☐ Is the path leading to it clear?
- ☐ Is it clean?
- ☐ Is it reasonably free of smell?
- ☐ Are there cleansing materials in the vicinity? What are they? _____
- ☐ Is there water in the vicinity?
- ☐ Is there ash in the vicinity?
- ☐ Any other evidence of use?

9. Is the latrine sanitary?

- ☐ yes-includes a clean squatting hole and slab, a well fitting lid or water seal, or screened vent-pipe, few flies)
- ☐ no-includes filled up pits, dirty hole or slab, severe fly problem)

10. How close are hand-washing facilities (water and ash or soap) to the latrine?

- ☐ next to the latrine
- ☐ within walking distance
- ☐ inside the house

11. Is there evidence of fecal contamination?

- ☐ along the roads?
- ☐ along the foot-paths?
- ☐ near the water source?
- ☐ in/near the fields?
- ☐ outside the houses?
- ☐ inside the houses?

12. What kind of contamination observed?

- ☐ infants/young children's faeces
- ☐ adults' faeces
- ☐ animal faeces
- ☐ refuse / trash
- ☐ other

13. Did you see anyone defecating? *yes / no*

☐ infants-children under 5
☐ adults
☐ animals
☐ other _____

14. On average, how far are the latrines from the water sources?

Latrine	Distance to Water Source
<input type="checkbox"/>	(a) less than 15 meters
<input type="checkbox"/>	(b) 15-50 meters
<input type="checkbox"/>	(c) 50-100 meters
<input type="checkbox"/>	(d) 100-200 meters
<input type="checkbox"/>	(e) 200-500 meters
<input type="checkbox"/>	(f) over 500 meters
<input type="checkbox"/>	(g) over 1km

15. Did you observe anyone disposing of waste water? *yes / no*

16. If yes, describe where, how, and by whom waste water was disposed of. _____

Vector Control

1. Is there stagnant water? _____

☐ near the water sources
☐ near the homes
☐ inside the homes
☐ near cooking

2. Is there a problem with insects? *yes / no* If yes, what types of insects?

☐ mosquitoes
☐ flies
☐ nats
☐ ants
☐ beetles
☐ cockroaches
☐ other (specify) _____

3. Are homes heavily infested with insects? *yes / no* If yes, what types of insects?

_____ mosquitoes
_____ flies
_____ nats
_____ ants
_____ beetles
_____ cockroaches
_____ other (specify) _____

4. Did you see evidence of rodents? *yes / no*

_____ rats
_____ rat droppings
_____ people with rat bites
_____ other _____

5. Did you see animals? *yes / no* If yes, what types?

_____ cats
_____ chickens
_____ cows
_____ dogs
_____ horses
_____ pigs
_____ sheep
_____ other _____

6. Where are the animals kept? Check all that apply and identify types.

_____ outside of the community _____
_____ inside the community _____
_____ in animal quarters inside the community _____
_____ in animal quarters outside the community _____
_____ roam freely _____

7. On average, how far are animals or evidence of animals from water sources?

Animals	Distance to water sources
	(a) less than 10 meters
	(b) 10-20 meters
	(c) 20-50 meters
	(d) 50-100 meters
	(e) 100-300 meters
	(f) 300-500 meters
	(g) over 500 meters

Recreation

1. Are children playing and participating in recreational activities?

yes / no

2. If yes, what types of leisure activities are children engaging in? (Specify and include materials being used)

_____ reading or writing _____
 _____ arts and crafts _____
 _____ card games _____
 _____ sports or recreation _____
 _____ tag games _____
 _____ other (list all that are observed) _____

3. Are adults participating in leisure or recreational activities?

yes / no

4. If yes, what types of leisure/recreational activities are adults engaging in? (specify)

_____ reading or writing _____
 _____ arts and crafts _____
 _____ card games _____
 _____ sports or recreation _____
 _____ other (list all that are observed) _____

5. Were leisure/recreational activities observed within 5 meters to...

- ☐ stagnant water
- ☐ latrines
- ☐ refuse / garbage
- ☐ water sources
- ☐ animal quarters *indicate type* _____
- ☐ animals *indicate type* _____
- ☐ rodents or rodent droppings
- ☐ standing sewage
- ☐ other _____

Additional Observations, Comments or Concerns

APPENDIX C

HOUSEHOLD QUESTIONNAIRE FOR DALLAS/PATA RAT
ENGLISH VERSION

Household Questionnaire for Dallas/Pata Rat – English Version

Hello, would you be willing to take 10-15 minutes to answer some questions regarding your health and community environment? Yes / No

No personal identifying information will be asked nor will information be used in any way that would cause you harm. Information will be used to help identify things in your environment that may be affecting your health and quality of life.

1. How many people live in your household?

- _____ Men
 _____ Women
 _____ Children age 5 and under
 _____ Children 6-14
 _____ Adolescents 15 and over

2. How long have you lived in Pata Rat?

- _____ less than one year
 _____ 1-2 years
 _____ 3-4 years
 _____ 5 or more years

3. Where are you from? _____

4. What are two health problems of greatest concern for you right now?

1. _____
 2. _____

5. What are two health problems of greatest concern for your children right now?

1. _____
 2. _____

6. Have you been sick in the last month?

Yes / No

7. If yes, what were two of your symptoms?

1. _____
 2. _____

8. Has your children been sick in the last month? Yes / No

9. If yes, what were two of their symptoms?

1. _____
2. _____

10. In the last year, how many times were you sick?

- _____ Zero
_____ 1-3
_____ 4-6
_____ 7-10
_____ More than 10 times

11. In the last year, how many times were your children sick?

- _____ Zero
_____ 1-3
_____ 4-6
_____ 7-10
_____ More than 10 times

12. Do you use home remedies? Yes / No

13. What home remedy do you use most often? _____

14. What do you use it for? _____

15. Are there things in your community that you think may have made you ill?
Yes / No

16. If yes, name 1-2 things.

1. _____
2. _____

17. Are there things in your community you would like to change? Yes / No

18. If yes, name 1-2 things.

1. _____
2. _____

19. Where would you like to see yourself in 5 years? _____

20. How do you imagine Pata Rat in 5 years? Is it the same or different?

- ☐ the same
☐ with more people
☐ not here
☐ haven't thought about it
☐ other (please specify) _____

21. How do you envision the future for your children? _____

22. How often do you find yourself worrying about the following issues?

	Never	Rarely	Sometimes	Often	Always
Feeling safe in your community (safety)					
Feeling safe outside of your community (safety)					
Having enough food (food security)					
Having enough money (economic security)					
Having access to preventative health care (health)					
Having access to medical care/treatment (health)					
Having weather proof housing (shelter)					

Thank you for taking the time to answer these questions. Information will be used to help identify things in your environment that may be affecting your health and quality of life. This will help determine your community's needs and how those needs can be met to improve your health and well-being.

APPENDIX D

HOUSEHOLD QUESTIONNAIRE FOR DALLAS/PATA RAT
ROMANIAN VERSION

Chestionar pentru Pata Rat

Buna ziua, doriti sa imi acordati 5-10 minute to pentru a raspunde la cateva intrebari despre sanatate si mediul din comunitatea dumneavoastra? Da / Nu

Nu este nevoie de informatii personale, iar informatiile obtinute nu vor fi folosite pentru a va face rau. Informatia obtinuta va fi folosita doar pentru a identifica lucruri din mediul dumneavoastra care v-ar putea afecta sanatatea si stilul de viata.

1. Cate personae locuiesc in casa d-voastra?
 - _____ Barbati
 - _____ Femei
 - _____ Copii cu varsta pana la 5 ani inclusive
 - _____ Copii 6-14
 - _____ Adolescenti de 15 ani si peste
2. De cat timp locuiti in Pata Rat?
 - _____ mai putin de 1 an
 - _____ 1-2 ani
 - _____ 3-4 ani
 - _____ 5 ani sau mai mult
3. De unde sunteti? _____
4. Care ar fi 2 probleme de sanatate care va ingrijoreaza chiar acum?
 - 1. _____
 - 2. _____
5. Care ar fi 2 probleme de sanatate care va ingrijoreaza la copii in acest moment?
 - 1. _____
 - 2. _____
6. A-ti fost bolnav in ultima luna? Da / Nu
7. Daca da, spuneti doua simptome?
 - 1. _____
 - 2. _____
8. La copii fost bolnav in ultima luna? Da / Nu

9. Daca da, spuneti doua simptome?
1. _____
2. _____
10. In ultimul an de cate ori a-ti fost bolnav (a)?
_____ Zero
_____ 1-3
_____ 4-6
_____ 7-10
_____ Mai mult de 10 ori
11. In ultimul an, de cate ori au fost copii d-voastra bolnavi?
_____ Zero
_____ 1-3
_____ 4-6
_____ 7-10
_____ Mai mult de 10 ori
12. Folositi leacuri/ medicamente facute acasa? Da / Nu
13. Ce fel de leac folositi cel mai des? _____

14. Pentru ce il folositi? _____
15. Sunt lucruri in comunitatea d-voastra care credeti ca v-au inbolnavit?
Da / Nu
16. Daca da, numiti 1-2 lucruri.
1. _____
2. _____
17. Sunt lucruri in comunitatea d-voastra pe care a-ti dori sa le schimbati? Da / Nu
18. Daca da, numiti 1-2 lucruri.
1. _____
2. _____
19. Unde v-ar placea sa fiti peste 5 ani? _____

20. Cum va imaginati ca va fi Pata-Rat-ul peste 5 ani? O sa fie la fel sau diferit?
_____ la fel

_____ cu mai multi oameni
 _____ nu va ma fi aici
 _____ nu m-am gandit
 _____ altele (va rog specificati) _____

21. Cum vedeti viitorul copiilor aici? _____

22. Cat de des va ingrijorati despre urmatoarele lucruri ?

	Nicioadata	Rar	Cateodata	Des	Intotdeauna
A fi in siguranta in comunitate					
A fi in siguranta in afara comunitatii					
A avea destula mancare (siguranta hranei)					
A avea destui bani (siguranta economica)					
Accesul la modalitati de ingrijire a sanatatii (sanatate)					
Acces la ingrijire medicale /tatment (sanatate)					
A avea o casa rezistenta (adapost)					

Va multumesc pentru timpul acordat pentru a raspunde la aceste intrebari. Informatia obtinuta va fi folosita pentru a identifica lucruri din mediul dumneavoastra care v-ar putea afecta sanatatea si stilul de viata.. Aceste informatii vor fi de ajutor pentru a estima nevoile comunitatii dumneavoastra si pentru a vedea cum pot fi aceste nevoi implinite pentru a imbunatatii sanatatea si starea d-voastra.

APPENDIX E

COMMUNITY MAPPING
ACTIVITY DESCRIPTION

Activity: Community Mapping

Timeframe: Monday, May 18, 2009 at 6pm for approximately 1-2 hours

Participants: All ages or smaller groups by gender or age. Adults were invited at yesterday's opening and will help in gaining trust from the elders in the community. However, all are welcome to participate.

Purpose: To map community and potential environmental hazards

Place: Flat dirt area next to YVM/FAF's New Life Education Center

Materials: Rocks, sticks, random materials, allow for people to make suggestions

Process: Explain who I (Jenny) am and that I would like their help in making map. Explain that the purpose is to help me identify possible environmental hazards in their community. Allow time for questions or discussions because participants may be skeptical of their ability to do the activity, especially if they have never been to school. If necessary, I and translator will begin the process with central landmark, roads or boundaries using a stick to draw on the ground. Then will 'hand over the stick' as much as possible to participants. Transcribe on paper and ask participants where they would like to keep it.

Map Making: Facilitators/Translators help participants get started and withdraw. Only provide input when required.

Discussion: Voice record and take notes of key points of participant's discussion while making the map. Need to listen carefully to what people are discussing. Discussion should be encouraged and allowed to be free and open for debate.

Presentation: Discuss map including observations, comparisons and things learned.

Record: When, where and who took part. Record map properties (size, width/length, materials used, key of symbols) and take pictures. Transcribe the map on paper. Use symbols, rather than words for participants that can't read. Make table with quantifiable data where possible.

Things that can be mapped: Roads, boundaries, water sources, latrines, open defecation sites, waste piles (solid waste management), houses, animal living quarters, private/public places, buildings, leader's homes, areas of poor drainage (stagnant water), markets, health center/clinic, church

- Activities: Where people do things, places they visit or get together
- Hazards: Identifies risks and capacities; Shows vulnerability to natural/environmental hazards
- Land Use and Resources: What happened where (e.g. laundry, bathing, cooking, recreation)
- Mental: How people/participants perceive their area; Useful insight to their perception

Closing: Thank everyone for their participation. Jenny will look over map and use it as a reference to identify possible environmental hazards that may be affecting their health, well-being and quality of life.

APPENDIX F

A SUMMARY OF THE RIGHTS UNDER THE
CONVENTION ON THE RIGHTS OF THE CHILD

UNICEF FACT SHEET

Article 1 (Definition of the child): The Convention defines a 'child' as a person below the age of 18, unless the laws of a particular country set the legal age for adulthood younger. The Committee on the Rights of the Child, the monitoring body for the Convention, has encouraged States to review the age of majority if it is set below 18 and to increase the level of protection for all children under 18.

Article 2 (Non-discrimination): The Convention applies to all children, whatever their race, religion or abilities; whatever they think or say, whatever type of family they come from. It doesn't matter where children live, what language they speak, what their parents do, whether they are boys or girls, what their culture is, whether they have a disability or whether they are rich or poor. No child should be treated unfairly on any basis.

Article 3 (Best interests of the child): The best interests of children must be the primary concern in making decisions that may affect them. All adults should do what is best for children. When adults make decisions, they should think about how their decisions will affect children. This particularly applies to budget, policy and law makers.

Article 4 (Protection of rights): Governments have a responsibility to take all available measures to make sure children's rights are respected, protected and fulfilled. When countries ratify the Convention, they agree to review their laws relating to children. This involves assessing their social services, legal, health and educational systems, as well as levels of funding for these services. Governments are then obliged to take all necessary steps to ensure that the minimum standards set by the Convention in these areas are being met. They must help families protect children's rights and create an environment where they can grow and reach their potential. In some instances, this may involve changing existing laws or creating new ones. Such legislative changes are not imposed, but come about through the same process by which any law is created or reformed within a country. Article 41 of the Convention points out the when a country already has higher legal standards than those seen in the Convention, the higher standards always prevail.

Article 5 (Parental guidance): Governments should respect the rights and responsibilities of families to direct and guide their children so that, as they grow, they learn to use their rights properly. Helping children to understand their rights does not mean pushing them to make choices with consequences that they are too young to handle. Article 5 encourages parents to deal with rights issues "in a manner consistent with the evolving capacities of the child." The Convention does not take responsibility for children away from their parents and give more authority to governments. It does place on governments the responsibility to protect and assist families in fulfilling their essential role as nurturers of children.

Article 6 (Survival and development): Children have the right to live. Governments should ensure that children survive and develop healthily.

Article 7 (Registration, name, nationality, care): All children have the right to a legally registered name, officially recognised by the government. Children have the right to a nationality (to belong to a country). Children also have the right to know and, as far as possible, to be cared for by their parents.

Article 8 (Preservation of identity): Children have the right to an identity – an official record of who they are. Governments should respect children’s right to a name, a nationality and family ties.

Article 9 (Separation from parents): Children have the right to live with their parent(s), unless it is bad for them. Children whose parents do not live together have the right to stay in contact with both parents, unless this might hurt the child.

Article 10 (Family reunification): Families whose members live in different countries should be allowed to move between those countries so that parents and children can stay in contact, or get back together as a family.

Article 11 (Kidnapping): Governments should take steps to stop children being taken out of their country illegally. This article is particularly concerned with parental abductions. The Convention’s Optional Protocol on the sale of children, child prostitution and child pornography has a provision that concerns abduction for financial gain.

Article 12 (Respect for the views of the child): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account. This does not mean that children can now tell their parents what to do. This Convention encourages adults to listen to the opinions of children and involve them in decision-making – not give children authority over adults. Article 12 does not interfere with parents’ right and responsibility to express their views on matters affecting their children. Moreover, the Convention recognizes that the level of a child’s participation in decisions must be appropriate to the child’s level of maturity. Children’s ability to form and express their opinions develops with age and most adults will naturally give the views of teenagers greater weight than those of a preschooler, whether in family, legal or administrative decisions.

Article 12 (Respect for the views of the child): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.

Article 13 (Freedom of expression): Children have the right to get and share information, as long as the information is not damaging to them or others. In exercising the right to freedom of expression, children have the responsibility to also respect the rights, freedoms and reputations of others. The freedom of expression includes the right to share information in any way they choose, including by talking, drawing or writing.

Article 14 (Freedom of thought, conscience and religion): Children have the right to think and believe what they want and to practice their religion, as long as they are not stopping other people from enjoying their rights. Parents should help guide their children in these matters. The Convention respects the rights and duties of parents providing religious and moral guidance to their children. Religious groups around the world have expressed support for the Convention, which indicates that it in no way prevents parents from bringing their children up within a religious tradition. At the same time, the Convention recognizes that as children mature and are able to form their own views, some may question certain religious practices or cultural traditions. The Convention supports children's right to examine their beliefs, but it also states that their right to express their beliefs implies respect for the rights and freedoms of others.

Article 15 (Freedom of association): Children have the right to meet together and to join groups and organizations, as long as it does not stop other people from enjoying their rights. In exercising their rights, children have the responsibility to respect the rights, freedoms and reputations of others.

Article 16 (Right to privacy): Children have a right to privacy. The law should protect them from attacks against their way of life, their good name, their families and their homes.

Article 17 (Access to information; mass media): Children have the right to get information that is important to their health and well-being. Governments should encourage mass media-radio, television, newspapers and Internet content sources – to provide information that children can understand and to not promote materials that could harm children. Mass media should particularly be encouraged to supply information in languages that minority and indigenous children can understand. Children should also have access to children's books.

Article 18 (Parental responsibilities; state assistance): Both parents share responsibility for bringing up their children, and should always consider what is best for each child. Governments must respect the responsibility of parents for providing appropriate guidance to their children – the Convention does not take responsibility for children away from their parents and give more authority to governments. It places a responsibility on governments to provide support services to parents, especially if both parents work outside the home.

Article 19 (Protection from all forms of violence): Children have the right to be protected from being hurt and mistreated, physically or mentally. Governments should ensure that children are properly cared for and protect them from violence, abuse and neglect by their parents, or anyone else who looks after them in terms of discipline, the Convention does not specify what forms of punishment parents should use. However any form of discipline involving violence is unacceptable. There are ways to discipline children that are effective in helping children learn about family and social expectations for their behavior – one that are non-violent, are appropriate to the child's level of development and take the best interests of the child into consideration. In most countries,

laws already define what sorts of punishments are considered excessive or abusive. It is up to each government to review these laws in light of the Convention.

Article 20 (Children deprived of family environment): Children who cannot be looked after by their own family have a right to special care and must be looked after properly, by people who respect their ethnic group, religion, culture and language.

Article 21 (Adoption): Children have the right to care and protection if they are adopted or in foster care. The first concern must be what is best for them. The same rules should apply whether they are adopted in the country where they were born, or if they are taken to live in another country.

Article 22 (Refugee children): Children have the right to special protection and help if they are refugees (if they have been forced to leave their home and live in another country), as well as all the rights in this Convention.

Article 23 (Children with disabilities): Children who have any kind of disability have the right to special care and support, as well as all the rights in the Convention, so that they can live full and independent lives.

Article 24 (Health and health services): Children have the right to good quality health care – the best health care possible – to safe drinking water, nutritious food, a clean and safe environment, and information to help them stay healthy. Rich countries should help poorer countries achieve this.

Article 25 (Review of treatment in care): Children who are looked after by their local authorities, rather than their parents, have the right to have these living arrangements looked at regularly to see if they are the most appropriate. Their care and treatment should always be based on “the best interests of the child.” (see Guiding Principles, Article 3)

Article 26 (Social security): Children – either through their guardians or directly – have the right to help from the government if they are poor or in need.

Article 27 (Adequate standard of living): Children have the right to a standard of living that is good enough to meet their physical and mental needs. Governments should help families and guardians who cannot afford to provide this, particularly with regard to food, clothing and housing.

Article 28: (Right to education): All children have the right to a primary education, which should be free. Wealthy countries should help poorer countries achieve this right. Discipline in schools should respect children’s dignity. For children to benefit from education, schools must be run in an orderly way – without the use of violence. Any form of school discipline should take into account the child’s human dignity. Therefore, governments must ensure that school administrators review their discipline policies and eliminate any discipline practices involving physical or mental violence, abuse or neglect.

The Convention places a high value on education. Young people should be encouraged to reach the highest level of education of which they are capable.

Article 29 (Goals of education): Children's education should develop each child's personality, talents and abilities to the fullest. It should encourage children to respect others, human rights and their own and other cultures. It should also help them learn to live peacefully, protect the environment and respect other people. Children have a particular responsibility to respect the rights their parents, and education should aim to develop respect for the values and culture of their parents. The Convention does not address such issues as school uniforms, dress codes, the singing of the national anthem or prayer in schools. It is up to governments and school officials in each country to determine whether, in the context of their society and existing laws, such matters infringe upon other rights protected by the Convention.

Article 30 (Children of minorities/indigenous groups): Minority or indigenous children have the right to learn about and practice their own culture, language and religion. The right to practice one's own culture, language and religious applies to everyone; the Convention here highlights this right in instances where the practices are not shared by the majority of people in the country.

Article 31 (Leisure, play and culture): Children have the right to relax and play, and to join in a wide range of cultural, artistic and other recreational activities.

Article 32 (Child labour): The government should protect children from work that is dangerous or might harm their health or their education. While the Convention protects children from harmful and exploitative work, there is nothing in it that prohibits parents from expecting their children help out at home in ways that are safe and appropriate to their age. If children help out in a family farm or business, the tasks they do be safe and suited to their level of development and comply with national labour laws. Children's work should not jeopardize any of their other rights, including the right to education, or the right to relaxation and play.

Article 33 (Drug abuse): Governments should use all means possible to protect children from the use of harmful drugs and from being used in the drug trade.

Article 34 (Sexual exploitation): Governments should protect children from all forms of sexual exploitation and abuse. This provision in the Convention is augmented by the Optional Protocol on the sale of children, child prostitution and child pornography.

Article 35 (Abduction, sale and trafficking): The government should take all measures possible to make sure that children are not abducted, sold or trafficked. This provision in the Convention is augmented by the Optional Protocol on the sale of children, child prostitution and child pornography.

Article 36 (Other forms of exploitation): Children should be protected from any activity that takes advantage of them or could harm their welfare and development.

Article 37 (Detention and punishment): No one is allowed to punish children in a cruel or harmful way. Children who break the law should not be treated cruelly. They should not be put in prison with adults, should be able to keep in contact with their families, and should not be sentenced to death or life imprisonment without possibility of release.

Article 38 (War and armed conflicts): Governments must do everything they can to protect and care for children affected by war. Children under 15 should not be forced or recruited to take part in a war or join the armed forces. The Convention's Optional Protocol on the involvement of children in armed conflict further develops this right, raising the age for direct participation in armed conflict to 18 and establishing a ban on compulsory recruitment for children under 18.

Article 39 (Rehabilitation of child victims): Children who have been neglected, abused or exploited should receive special help to physically and psychologically recover and reintegrate into society. Particular attention should be paid to restoring the health, self-respect and dignity of the child.

Article 40 (Juvenile justice): Children who are accused of breaking the law have the right to legal help and fair treatment in a justice system that respects their rights. Governments are required to set a minimum age below which children cannot be held criminally responsible and to provide minimum guarantees for the fairness and quick resolution of judicial or alternative proceedings.

Article 41 (Respect for superior national standards): If the laws of a country provide better protection of children's rights than the articles in this Convention, those laws should apply.

Article 42 (Knowledge of rights): Governments should make the Convention known to adults and children. Adults should help children learn about their rights, too. (See also article 4.)

Articles 43-54 (implementation measures): These articles discuss how governments and international organizations like UNICEF should work to ensure children are protected in their rights

APPENDIX G

UNIVERSAL DECLARATION OF HUMAN RIGHTS

PREAMBLE

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,

Whereas disregard and contempt for human rights have resulted in barbarous acts which have outraged the conscience of mankind, and the advent of a world in which human beings shall enjoy freedom of speech and belief and freedom from fear and want has been proclaimed as the highest aspiration of the common people,

Whereas it is essential, if man is not to be compelled to have recourse, as a last resort, to rebellion against tyranny and oppression, that human rights should be protected by the rule of law,

Whereas it is essential to promote the development of friendly relations between nations,

Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom,

Whereas Member States have pledged themselves to achieve, in cooperation with the United Nations, the promotion of universal respect for and observance of human rights and fundamental freedoms,

Whereas a common understanding of these rights and freedoms is of the greatest importance for the full realization of this pledge,

Now, therefore,
The General Assembly

Proclaims

This Universal Declaration of Human Rights

as a common standard of achievement for all peoples and all nations, to the end that every individual and every organ of society, keeping this Declaration constantly in mind, shall strive by teaching and education to promote respect for these rights and freedoms and by progressive measures, national and international, to secure their universal and

effective recognition and observance, both among the peoples of Member States themselves and among the peoples of territories under their jurisdiction.

Article I

All human beings are born free and equal in dignity and rights. They are endowed with reason and conscience and should act towards one another in a spirit of brotherhood.

Article 2

Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.

Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty.

Article 3

Everyone has the right to life, liberty and security of person.

Article 4

No one shall be held in slavery or servitude; slavery and the slave trade shall be prohibited in all their forms.

Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

Article 6

Everyone has the right to recognition everywhere as a person before the law.

Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination.

Article 8

Everyone has the right to an effective remedy by the competent national tribunals for acts violating the fundamental rights granted him by the constitution or by law.

Article 9

No one shall be subjected to arbitrary arrest, detention or exile.

Article 10

Everyone is entitled in full equality to a fair and public hearing by an independent and impartial tribunal, in the determination of his rights and obligations and of any criminal charge against him.

Article 11

(1) Everyone charged with a penal offence has the right to be presumed innocent until proved guilty according to law in a public trial at which he has had all the guarantees necessary for his defence.

(2) No one shall be held guilty of any penal offence on account of any act or omission which did not constitute a penal offence, under national or international law, at the time when it was committed. Nor shall a heavier penalty be imposed than the one that was applicable at the time the penal offence was committed.

Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.

Article 13

(1) Everyone has the right to freedom of movement and residence within the borders of each State.

(2) Everyone has the right to leave any country, including his own, and to return to his country.

Article 14

(1) Everyone has the right to seek and to enjoy in other countries asylum from persecution.

(2) This right may not be invoked in the case of prosecutions genuinely arising from non-political crimes or from acts contrary to the purposes and principles of the United Nations.

Article 15

(1) Everyone has the right to a nationality.

(2) No one shall be arbitrarily deprived of his nationality nor denied the right to change his nationality.

Article 16

(1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

(2) Marriage shall be entered into only with the free and full consent of the intending spouses.

(3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the State.

Article 17

(1) Everyone has the right to own property alone as well as in association with others.

(2) No one shall be arbitrarily deprived of his property.

Article 18

Everyone has the right to freedom of thought, conscience and religion; this right includes freedom to change his religion or belief, and freedom, either alone or in community with others and in public or private, to manifest his religion or belief in teaching, practice, worship and observance.

Article 19

Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

Article 20

- (1) Everyone has the right to freedom of peaceful assembly and association.
- (2) No one may be compelled to belong to an association.

Article 21

- (1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
- (2) Everyone has the right to equal access to public service in his country.
- (3) The will of the people shall be the basis of the authority of government; this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures.

Article 22

Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural rights indispensable for his dignity and the free development of his personality.

Article 23

- (1) Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment.
- (2) Everyone, without any discrimination, has the right to equal pay for equal work.
- (3) Everyone who works has the right to just and favourable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection.
- (4) Everyone has the right to form and to join trade unions for the protection of his interests.

Article 24

Everyone has the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.

Article 25

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

Article 26

(1) Everyone has the right to education. Education shall be free, at least in the elementary and fundamental stages. Elementary education shall be compulsory. Technical and professional education shall be made generally available and higher education shall be equally accessible to all on the basis of merit.

(2) Education shall be directed to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. It shall promote understanding, tolerance and friendship among all nations, racial or religious groups, and shall further the activities of the United Nations for the maintenance of peace.

(3) Parents have a prior right to choose the kind of education that shall be given to their children.

Article 27

(1) Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.

(2) Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.

Article 28

Everyone is entitled to a social and international order in which the rights and freedoms set forth in this Declaration can be fully realized.

Article 29

(1) Everyone has duties to the community in which alone the free and full development of his personality is possible.

(2) In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

(3) These rights and freedoms may in no case be exercised contrary to the purposes and principles of the United Nations.

Article 30

Nothing in this Declaration may be interpreted as implying for any State, group or person any right to engage in any activity or to perform any act aimed at the destruction of any of the rights and freedoms set forth herein.

G.A. res. 217A (III), U.N. Doc A/810 at 71 (1948)

Adopted on December 10, 1948
by the General Assembly of the United Nations (without dissent)

APPENDIX H

DRAFT DECLARATION ON HUMAN RIGHTS AND THE ENVIRONMENT

Draft Principles On Human Rights And The Environment, E/CN.4/Sub.2/1994/9, Annex I (1994). Principles only, without commentary

On 16 May 1994, an international group of experts on human rights and environmental protection convened at the United Nations in Geneva and drafted the first-ever declaration of principles on human rights and the environment.

The Geneva group assembled at the invitation of the Sierra Club Legal Defense Fund--in cooperation with the Association mondiale pour l'école instrument de paix and the Société suisse pour la protection de l'environnement--on behalf of Madame Fatma Zohra Ksentini, Special Rapporteur on Human Rights and the Environment for the United Nations Sub-Commission on Prevention of Discrimination and Protection of Minorities.

As U.N. Special Rapporteur, Mme Ksentini has since 1989 presided over a study of the connections between human rights and the environment. Mme Ksentini's final report to the Sub-Commission is due in August 1994. The final report will include the Draft Declaration produced at the Geneva Meeting of Experts.

The Draft Declaration is the first international instrument that comprehensively addresses the linkage between human rights and the environment. It demonstrates that accepted environmental and human rights principles embody the right of everyone to a secure, healthy and ecologically sound environment. The Draft Declaration describes the environmental dimension of established human rights, such as the rights to life, health and culture. It also describes the procedural rights, such as the right to participation, necessary for realization of the substantive rights.

The Draft Declaration also describes duties that correspond to the rights--duties that apply to individuals, governments, international organizations and transnational corporations.

Preamble

Guided by the United Nations Charter, the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Vienna Declaration and Program of Action of the World Conference of Human Rights, and other relevant international human rights instruments,

Guided also by the Stockholm Declaration of the United Nations Conference on the Human Environment, the World Charter for Nature, the Rio Declaration on Environment

and Development, Agenda 21: Programme of Action for Sustainable Development, and other relevant instruments of international environmental law,

Guided also by the Declaration on the Right to Development, which recognizes that the right to development is an essential human right and that the human person is the central subject of development,

Guided further by fundamental principles of international humanitarian law,

Reaffirming the universality, indivisibility and interdependence of all human rights,

Recognizing that sustainable development links the right to development and the right to a secure, healthy and ecologically sound environment,

Recalling the right of peoples to self-determination by virtue of which they have the right freely to determine their political status and to pursue their economic, social and cultural development,

Deeply concerned by the severe human rights consequences of environmental harm caused by poverty, structural adjustment and debt programmes and by international trade and intellectual property regimes,

Convinced that the potential irreversibility of environmental harm gives rise to special responsibility to prevent such harm,

Concerned that human rights violations lead to environmental degradation and that environmental degradation leads to human rights violations,

THE FOLLOWING PRINCIPLES ARE DECLARED:

Part I

1. Human rights, an ecologically sound environment, sustainable development and peace are interdependent and indivisible.
2. All persons have the right to a secure, healthy and ecologically sound environment. This right and other human rights, including civil, cultural, economic, political and social rights, are universal, interdependent and indivisible.
3. All persons shall be free from any form of discrimination in regard to actions and decisions that affect the environment.

4. All persons have the right to an environment adequate to meet equitably the needs of present generations and that does not impair the rights of future generations to meet equitably their needs.

Part II

5. All persons have the right to freedom from pollution, environmental degradation and activities that adversely affect the environment, threaten life, health, livelihood, well-being or sustainable development within, across or outside national boundaries.

6. All persons have the right to protection and preservation of the air, soil, water, sea-ice, flora and fauna, and the essential processes and areas necessary to maintain biological diversity and ecosystems.

7. All persons have the right to the highest attainable standard of health free from environmental

8. All persons have the right to safe and healthy food and water adequate to their well-being.

9. All persons have the right to a safe and healthy working environment.

10. All persons have the right to adequate housing, land tenure and living conditions in a secure, healthy and ecologically sound environment.

11 . All persons have the right not to be evicted from their homes or land for the purpose of, or as a consequence of, decisions or actions affecting the environment, except in emergencies or due to a compelling purpose benefiting society as a whole and not attainable by other means. All persons have the right to participate effectively in decisions and to negotiate concerning their eviction and the right, if evicted, to timely and adequate restitution, compensation and/or appropriate and sufficient accommodation or land.

12. All persons have the right to timely assistance in the event of natural or technological or other human-caused catastrophes.

13. Everyone has the right to benefit equitably from the conservation and sustainable use of nature and natural resources for cultural, ecological, educational, health, livelihood, recreational, spiritual or other purposes. This Includes ecologically sound access to nature.

Everyone has the right to preservation of unique sites, consistent with the fundamental rights of persons or groups living in the area.

14. Indigenous peoples have the right to control their lands, territories and natural resources and to maintain their traditional way of life. This includes the right to security in the enjoyment of their means of subsistence.

Indigenous peoples have the right to protection against any action or course of conduct that may result in the destruction or degradation of their territories, including land, air, water, sea-ice, wildlife or other resources.

Part III

15. All persons have the right to information concerning the environment. This includes information, howsoever compiled, on actions and courses of conduct that may affect the environment and information necessary to enable effective public participation in environmental decision-making. The information shall be timely, clear, understandable and available without undue financial burden to the applicant.

16. All persons have the right to hold and express opinions and to disseminate ideas and information regarding the environment.

17. All persons have the right to environmental and human rights education.

18. All persons have the right to active, free, and meaningful participation in planning and decision-making activities and processes that may have an impact on the environment and development. This includes the right to a prior assessment of the environmental, developmental and human rights consequences of proposed actions.

19. All persons have the right to associate freely and peacefully with others for purposes of protecting the environment or the rights of persons affected by environmental harm.

20. All persons have the right to effective remedies and redress in administrative or judicial proceedings for environmental harm or the threat of such harm.

Part IV

21. All persons, individually and in association with others, have a duty to protect and preserve the environment.

22. All States shall respect and ensure the right to a secure, healthy and ecologically sound environment. Accordingly, they shall adopt the administrative, legislative and other measures necessary to effectively implement the rights in this Declaration.

These measures shall aim at the prevention of environmental harm, at the provision of adequate remedies, and at the sustainable use of natural resources and shall include, *inter alia*,

- collection and dissemination of information concerning the environment
- prior assessment and control, licensing, regulation or prohibition of activities and substances potentially harmful to the environment;
- public participation in environmental decision-making;
- effective administrative and judicial remedies and redress for environmental harm and the threat of such harm;
- monitoring, management and equitable sharing of natural resources;
- measures to reduce wasteful processes of production and patterns of consumption;
- measures aimed at ensuring that transnational corporations, wherever they operate, carry out their duties of environmental protection, sustainable development and respect for human rights; and
- measures aimed at ensuring that the international organizations and agencies to which they belong observe the rights and duties in this Declaration.

23. States and all other parties shall avoid using the environment as a means of war or inflicting significant, long-term or widespread harm on the environment, and shall respect international law providing protection for the environment in times of armed conflict and cooperate in its further development.

24. All international organizations and agencies shall observe the rights and duties in this Declaration.

Part V

25. In implementing the rights and duties in this Declaration, special attention shall be given to vulnerable persons and groups.

26. The rights in this Declaration may be subject only to restrictions provided by law and which are necessary to protect public order, health and the fundamental rights and freedoms of others.

27. All persons are entitled to a social and international order in which the rights in this Declaration can be fully realized.

APPENDIX I

INTERNATIONAL ETHICAL GUIDELINES FOR BIOMEDICAL RESEARCH
INVOLVING HUMAN SUBJECTS

CIOMS, WHO, Geneva, 2002
Basic guidelines only, without commentary

Guideline 1: Ethical justification and scientific validity of biomedical research involving human beings

The ethical justification of biomedical research involving human subjects is the prospect of discovering new ways of benefiting people's health. Such research can be ethically justifiable only if it is carried out in ways that respect and protect, and are fair to, the subjects of that research and are morally acceptable within the communities in which the research is carried out. Moreover, because scientifically invalid research is unethical in that it exposes research subjects to risks without possible benefit, investigators and sponsors must ensure that proposed studies involving human subjects conform to generally accepted scientific principles and are based on adequate knowledge of the pertinent scientific literature.

Guideline 2: Ethical review committees

All proposals to conduct research involving human subjects must be submitted for review of their scientific merit and ethical acceptability to one or more scientific review and ethical review committees. The review committees must be independent of the research team, and any direct financial or other material benefit they may derive from the research should not be contingent on the outcome of their review. The investigator must obtain their approval or clearance before undertaking the research. The ethical review committee should conduct further reviews as necessary in the course of the research, including monitoring of the progress of the study.

Guideline 3: Ethical review of externally sponsored research

An external sponsoring organization and individual investigators should submit the research protocol for ethical and scientific review in the country of the sponsoring organization, and the ethical standards applied should be no less stringent than they would be for research carried out in that country. The health authorities of the host country, as well as a national or local ethical review committee, should ensure that the proposed research is responsive to the health needs and priorities of the host country and meets the requisite ethical standards.

Guideline 4: Individual informed consent

For all biomedical research involving humans the investigator must obtain the voluntary informed consent of the prospective subject or, in the case of an individual who is not capable of giving informed consent, the permission of a legally authorized representative in accordance with applicable law. Waiver of informed consent is to be regarded as uncommon and exceptional, and must in all cases be approved by an ethical review committee.

Guideline 5: Obtaining informed consent: Essential information for prospective research subjects

Before requesting an individual's consent to participate in research, the investigator must provide the following information, in language or another form of communication that the individual can understand:

1. that the individual is invited to participate in research, the reasons for considering the individual suitable for the research, and that participation is voluntary;
2. that the individual is free to refuse to participate and will be free to withdraw from the research at any time without penalty or loss of benefits to which he or she would otherwise be entitled;
3. the purpose of the research, the procedures to be carried out by the investigator and the subject, and an explanation of how the research differs from routine medical care;
4. for controlled trials, an explanation of features of the research design (e.g., randomization, double-blinding), and that the subject will not be told of the assigned treatment until the study has been completed and the blind has been broken;
5. the expected duration of the individual's participation (including number and duration of visits to the research centre and the total time involved) and the possibility of early termination of the trial or of the individual's participation in it;
6. whether money or other forms of material goods will be provided in return for the individual's participation and, if so, the kind and amount;
7. that, after the completion of the study, subjects will be informed of the findings of the research in general, and individual subjects will be informed of any finding that relates to their particular health status;
8. that subjects have the right of access to their data on demand, even if these data lack immediate clinical utility (unless the ethical review committee has approved

temporary or permanent non-disclosure of data, in which case the subject should be informed of, and given, the reasons for such non-disclosure);

9. any foreseeable risks, pain or discomfort, or inconvenience to the individual (or others) associated with participation in the research, including risks to the health or well-being of a subject's spouse or partner;
10. the direct benefits, if any, expected to result to subjects from participating in the research
11. the expected benefits of the research to the community or to society at large, or contributions to scientific knowledge;
12. whether, when and how any products or interventions proven by the research to be safe and effective will be made available to subjects after they have completed their participation in the research, and whether they will be expected to pay for them;
13. any currently available alternative interventions or courses of treatment;
14. the provisions that will be made to ensure respect for the privacy of subjects and for the confidentiality of records in which subjects are identified;
15. the limits, legal or other, to the investigators' ability to safeguard confidentiality, and the possible consequences of breaches of confidentiality;
16. policy with regard to the use of results of genetic tests and familial genetic information, and the precautions in place to prevent disclosure of the results of a subject's genetic tests to immediate family relatives or to others (e.g., insurance companies or employers) without the consent of the subject;
17. the sponsors of the research, the institutional affiliation of the investigators, and the nature and sources of funding for the research;
18. the possible research uses, direct or secondary, of the subject's medical records and of biological specimens taken in the course of clinical care (See also Guidelines 4 and 18 Commentaries);
19. whether it is planned that biological specimens collected in the research will be destroyed at its conclusion, and, if not, details about their storage (where, how, for how long, and final disposition) and possible future use, and that subjects have the right to decide about such future use, to refuse storage, and to have the material destroyed (See Guideline 4 Commentary);

20. whether commercial products may be developed from biological specimens, and whether the participant will receive monetary or other benefits from the development of such products;
21. whether the investigator is serving only as an investigator or as both investigator and the subject's physician;
22. the extent of the investigator's responsibility to provide medical services to the participant;
23. that treatment will be provided free of charge for specified types of research-related injury or for complications associated with the research, the nature and duration of such care, the name of the organization or individual that will provide the treatment, and whether there is any uncertainty regarding funding of such treatment.
24. in what way, and by what organization, the subject or the subject's family or dependants will be compensated for disability or death resulting from such injury (or, when indicated, that there are no plans to provide such compensation);
25. whether or not, in the country in which the prospective subject is invited to participate in research, the right to compensation is legally guaranteed;
26. that an ethical review committee has approved or cleared the research protocol.

Guideline 6: Obtaining informed consent: Obligations of sponsors and investigators

Sponsors and investigators have a duty to:

- refrain from unjustified deception, undue influence, or intimidation;
- seek consent only after ascertaining that the prospective subject has adequate understanding of the relevant facts and of the consequences of participation and has had sufficient opportunity to consider whether to participate;
- as a general rule, obtain from each prospective subject a signed form as evidence of informed consent – investigators should justify any exceptions to this general rule and obtain the approval of the ethical review committee (See Guideline 4 Commentary, Documentation of consent);
- renew the informed consent of each subject if there are significant changes in the conditions or procedures of the research or if new information becomes available that could affect the willingness of subjects to continue to participate; and,
- renew the informed consent of each subject in long-term studies at pre-determined intervals, even if there are no changes in the design or objectives of the research.

Guideline 7: Inducement to participate

Subjects may be reimbursed for lost earnings, travel costs and other expenses incurred in taking part in a study; they may also receive free medical services. Subjects, particularly those who receive no direct benefit from research, may also be paid or otherwise compensated for inconvenience and time spent. The payments should not be so large, however, or the medical services so extensive as to induce prospective subjects to consent to participate in the research against their better judgment ("undue inducement"). All payments, reimbursements and medical services provided to research subjects must have been approved by an ethical review committee.

Guideline 8: Benefits and risks of study participation

For all biomedical research involving human subjects, the investigator must ensure that potential benefits and risks are reasonably balanced and risks are minimized.

- Interventions or procedures that hold out the prospect of direct diagnostic, therapeutic or preventive benefit for the individual subject must be justified by the expectation that they will be at least as advantageous to the individual subject, in the light of foreseeable risks and benefits, as any available alternative. Risks of such 'beneficial' interventions or procedures must be justified in relation to expected benefits to the individual subject.
- Risks of interventions that do not hold out the prospect of direct diagnostic, therapeutic or preventive benefit for the individual must be justified in relation to the expected benefits to society (generalizable knowledge). The risks presented by such interventions must be reasonable in relation to the importance of the knowledge to be gained.

Guideline 9: Special limitations on risk when research involves individuals who are not capable of giving informed consent

When there is ethical and scientific justification to conduct research with individuals incapable of giving informed consent, the risk from research interventions that do not hold out the prospect of direct benefit for the individual subject should be no more likely and not greater than the risk attached to routine medical or psychological examination of such persons. Slight or minor increases above such risk may be permitted when there is an overriding scientific or medical rationale for such increases and when an ethical review committee has approved them.

Guideline 10: Research in populations and communities with limited resources

Before undertaking research in a population or community with limited resources, the sponsor and the investigator must make every effort to ensure that:

- the research is responsive to the health needs and the priorities of the population or community in which it is to be carried out; and
- any intervention or product developed, or knowledge generated, will be made reasonably available for the benefit of that population or community.

Guideline 11: Choice of control in clinical trials

As a general rule, research subjects in the control group of a trial of a diagnostic, therapeutic, or preventive intervention should receive an established effective intervention. In some circumstances it may be ethically acceptable to use an alternative comparator, such as placebo or "no treatment."

Placebo may be used:

- when there is no established effective intervention;
- when withholding an established effective intervention would expose subjects to, at most, temporary discomfort or delay in relief of symptoms;
- when use of an established effective intervention as comparator would not yield scientifically reliable results and use of placebo would not add any risk of serious or irreversible harm to the subjects.

Guideline 12: Equitable distribution of burdens and benefits in the selection of groups of subjects in research

Groups or communities to be invited to be subjects of research should be selected in such a way that the burdens and benefits of the research will be equitably distributed. The exclusion of groups or communities that might benefit from study participation must be justified.

Guideline 13: Research involving vulnerable persons

Special justification is required for inviting vulnerable individuals to serve as research subjects and, if they are selected, the means of protecting their rights and welfare must be strictly applied.

Guideline 14: Research involving children

Before undertaking research involving children, the investigator must ensure that:

- the research might not equally well be carried out with adults;

- the purpose of the research is to obtain knowledge relevant to the health needs of children;
- a parent or legal representative of each child has given permission;
- the agreement (assent) of each child has been obtained to the extent of the child's capabilities; and,
- a child's refusal to participate or continue in the research will be respected.

Guideline 15: Research involving individuals who by reason of mental or behavioural disorders are not capable of giving adequately informed consent

Before undertaking research involving individuals who by reason of mental or behavioural disorders are not capable of giving adequately informed consent, the investigator must ensure that:

- such persons will not be subjects of research that might equally well be carried out on persons whose capacity to give adequately informed consent is not impaired;
- the purpose of the research is to obtain knowledge relevant to the particular health needs of persons with mental or behavioural disorders;
- the consent of each subject has been obtained to the extent of that person's capabilities, and a prospective subject's refusal to participate in research is always respected, unless, in exceptional circumstances, there is no reasonable medical alternative and local law permits overriding the objection; and,
- in cases where prospective subjects lack capacity to consent, permission is obtained from a responsible family member or a legally authorized representative in accordance with applicable law.

Guideline 16: Women as research subjects

Investigators, sponsors or ethical review committees should not exclude women of reproductive age from biomedical research. The potential for becoming pregnant during a study should not, in itself, be used as a reason for precluding or limiting participation. However, a thorough discussion of risks to the pregnant woman and to her fetus is a prerequisite for the woman's ability to make a rational decision to enrol in a clinical study. In this discussion, if participation in the research might be hazardous to a fetus or a woman if she becomes pregnant, the sponsors/ investigators should guarantee the prospective subject a pregnancy test and access to effective contraceptive methods before the research commences. Where such access is not possible, for legal or religious reasons,

investigators should not recruit for such possibly hazardous research women who might become pregnant.

Guideline 17: Pregnant women as research participants.

Pregnant women should be presumed to be eligible for participation in biomedical research. Investigators and ethical review committees should ensure that prospective subjects who are pregnant are adequately informed about the risks and benefits to themselves, their pregnancies, the fetus and their subsequent offspring, and to their fertility.

Research in this population should be performed only if it is relevant

to the particular health needs of a pregnant woman or her fetus, or to the health needs of pregnant women in general, and, when appropriate, if it is supported by reliable evidence from animal experiments, particularly as to risks of teratogenicity and mutagenicity .

Guideline 18: Safeguarding confidentiality

The investigator must establish secure safeguards of the confidentiality of subjects' research data. Subjects should be told the limits, legal or other, to the investigators' ability to safeguard confidentiality and the possible consequences of breaches of confidentiality.

Guideline 19: Right of injured subjects to treatment and compensation

Investigators should ensure that research subjects who suffer injury as a result of their participation are entitled to free medical treatment for such injury and to such financial or other assistance as would compensate them equitably for any resultant impairment, disability or handicap. In the case of death as a result of their participation, their dependants are entitled to compensation. Subjects must not be asked to waive the right to compensation.

Guideline 20: Strengthening capacity for ethical and scientific review and biomedical research

Many countries lack the capacity to assess or ensure the scientific quality or ethical acceptability of biomedical research proposed or carried out in their jurisdictions. In externally sponsored collaborative research, sponsors and investigators have an ethical obligation to ensure that biomedical research projects for which they are responsible in such countries contribute effectively to national or local capacity to design and conduct biomedical research, and to provide scientific and ethical review and monitoring of such research.

Capacity-building may include, but is not limited to, the following activities:

- establishing and strengthening independent and competent ethical review processes/ committees
- strengthening research capacity
- developing technologies appropriate to health-care and biomedical research
- training of research and health-care staff
- educating the community from which research subjects will be drawn

Guideline 21: Ethical obligation of external sponsors to provide health-care services

External sponsors are ethically obliged to ensure the availability of:

- health-care services that are essential to the safe conduct of the research;
- treatment for subjects who suffer injury as a consequence of research interventions; and,
- services that are a necessary part of the commitment of a sponsor to make a beneficial intervention or product developed as a result of the research reasonably available to the population or community concerned.